

STOLEN

A DAUGHTER'S CHRONOLOGY OF ALZHEIMER'S
DISEASE AND THE IMPACT OF IN-HOME-CARE.



LORA D. KING

FIRST EDITION

STOLEN

Lora D. King

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Stolen

by Lora D. King

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Carol
I hope you
find Stolen
informative
Lora D. King

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LORA D. KING

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To: Erin, Evan, Kyle, Dylan, and Karlyn (*Skylar*)

Dream big! Be willing to do whatever it takes to
accomplish your dream(s). Do not give up. He
will direct your steps.

Proverbs 3:5-6

Trust in the Lord with all thine heart, and lean
not unto thine own understanding.

In all thy ways acknowledge him and
He shall direct thy paths.

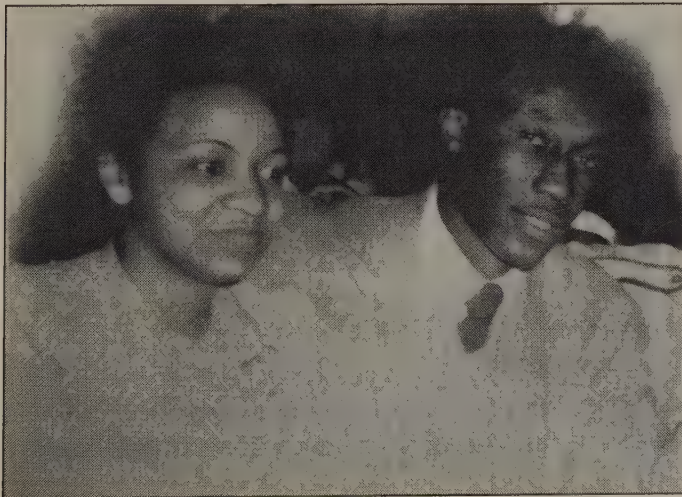
DEDICATION



Stolen, A Daughter's Chronology of Alzheimer's Disease and the Impact of In-Home-Care, is inspired by and dedicated to my father, Mr. Wince King Jr., an unsuspecting victim of a vicious degenerative brain disease that has robbed him of the memory of his 93 years on earth. Yet he wakes up everyday fearlessly, with a desire to contribute to his household and participate in this thing called life.

Stolen is also written in memory of our mother, Mrs. Marguerite King, whose marital partnership with our father spanned 58 years. Her name remains an indelible, unforgettable force in our father's mind to this day.

*"The memory of Dad's wife and our mother, Marguerite, endures.
Married 1942-2000."*



Stolen is also dedicated to all the Alzheimer's patients who deserve caregivers that are able to give them the compassion and joy necessary for them to live their lives with dignity and a sense of well-being.

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I must begin with thanking God and give the praise and glory to Him for the idea, my presence of mind to write this book, and its successful publication. Secondly, I want to express my sincere appreciation to my brother, Gregory King, for his unprecedented and unconditional love and admiration for our dad and his commitment and diligent work to keep him in his home. Next, the level of our dad's contentment and joy that he exhibits daily would not be possible without the quality of service, compassion, and dedication of our *caregivers with a calling*.

The people listed below are really the wind beneath my wings when it came to finishing this book. Most are probably not aware of their influence, yet it was something they said or did that resonated with me: your consistent inquiries about Dad's well-being; how your presence enhanced his life; our kindred experience in loving and caring for our parent(s); my observation and/or admiration of your relationship with and compassion for your parent(s); your encouraging telephone calls; or the smile in your voice or on your face when I said, "I'm writing a book about Dad." You know which one(s) you are. Thank you from the center of my heart.

Please forgive me if a name has been omitted, but I was told by my editor not to add another name:

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I am extremely grateful for the personal, passionate, and professional services of M2N Services, who turned my idea into a tangible reality – a book. Their services began with Kai EL’Zabar, the Executive Editor, who is dedicated to scheduling weekly meetings with her authors for however long until the client has a finished manuscript ready for print. Her dedication and creativity is unrelenting.

M2N’s creative team afforded me artist/illustrator Patrick Johnson, whose cover portrait of Dad took my breath away and who transformed my verbal and written visionary scenarios into tangible life-like Edu-illustrations; a special acknowledgement to my nephew, Evan King, whose initial sketches of Dad’s experiences gave impetus to Patrick’s final professional illustrations; and David Smallwood, copy editor, who dotted every “i” and crossed every “t”.

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FOREWORD



S *TOLEN* a compelling memoir of a sister and brother who as primary caregivers for their aging father who has AD, have navigated the challenges of a disease that has robbed him of all that is memorable except for his wife. Somehow he remembers “Marguerite.” Written in story form, it resonates with those who have lost loved ones to disease, death or are currently experiencing the “caregiver blues.” More than a story, *STOLEN* informs, prepares and educates in-home caregivers for the task of being in a relationship with the AD patient. It is a testament to commitment, integrity, and the love of one son and daughter for their father told to us by the sister. I wish I had this manual when my mother was traveling that AD journey.

Lora King’s book informs us that there is much dialog and discussion about Alzheimer’s, but in today’s world most of these messages are mere fragmented bits of information of the “big picture”. Let me make this point, doctors are not responsible for your health, you are. In a perfect world, each of us would be knowledgeable and aware of those things necessary and required of us to maintain our good health and heal ourselves when needed to do so. There are those of us in the medical field who feel that we must teach people to be healthy and train them to approach their bodies from a health mindset. This is a radical position and yet it is what I believe we should be striving to achieve.

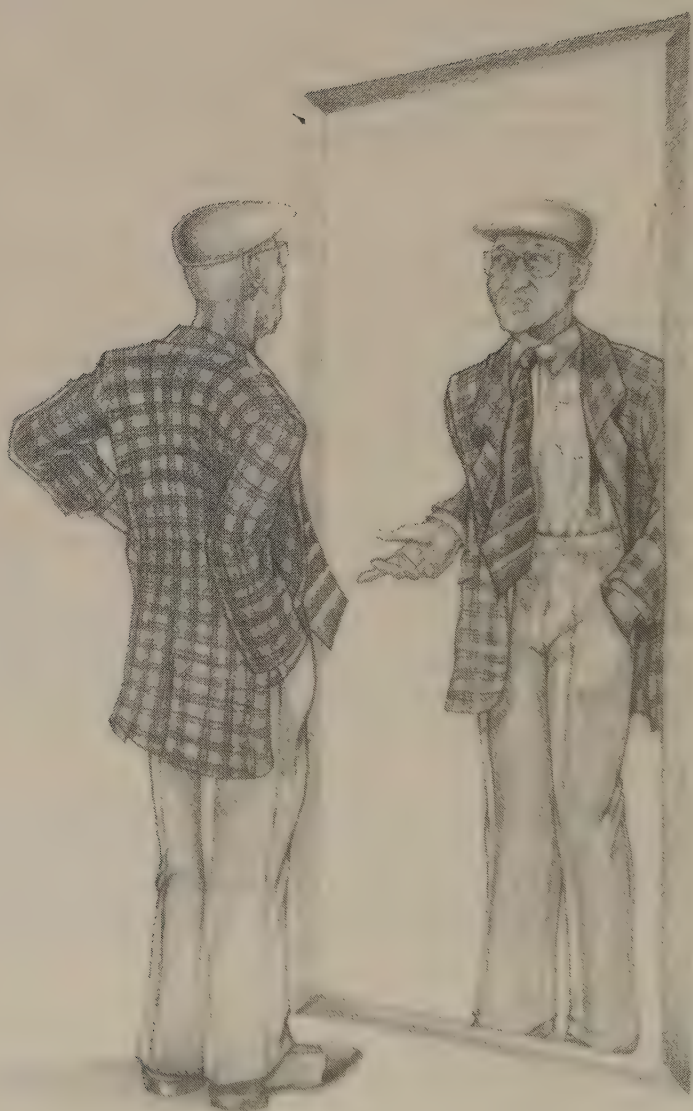
That’s what I love about *STOLEN*. Ms. King has accepted the responsibility for learning about her father’s illness and how to

better care for him in a way that he may maintain the best quality of life given the circumstances. She provides easy tasks and simple suggestions to improve our own health, and an in-depth guide that we can all follow to become better caregivers whether as a primary caregiver or a paid caregiver. She's gutsy and dares to say, that many have chosen the caregiver path as a job rather than seeking the higher ethical pursuit of the choice to give care with compassion. She calls them *caregivers with a calling*.

Ms. King asks some serious questions that ought to be considered of caregivers and those who may need care. I was moved, touched, and inspired by this chronicle of her journey because the love and respect for her father is always at the forefront, grounded in integrity and giving sustenance to authentic choices that she and her brother face and have to make where their father's well being is concerned. Consequently as a result of her research and experience, she has prepared us to take on the responsibility to empower ourselves by arming ourselves with information and taking steps to be better caregivers and better patients. My mother met the final stage as her body ceased to accept and process food for its nutrition and nourishment. She ceased to eat and it was the end coming. I saw it but I missed it. It hit me like a ton of bricks thrown at me. I know that had I had this book, I would have been better prepared.

STOLEN is the perfect handbook for us as caring human beings, rather than the doctor, lawyer, teacher, actor, preacher, fireman, policeman, as we often identify ourselves. "Ignorance is not bliss" as Ms. King kindly points out. So be prepared and enjoy the read.

~Dr. Herman Bell
Doctor of Osteopathic Medicine
and Author-*String of Perils*



PREFACE



One day I decided to take my father to my home to see if he could benefit from the physical activity of walking on my treadmill. At the time, I lived in a two-story townhouse. There was a large floor-to-ceiling mirror at the top of the second floor landing. My father and I were walking up the stairs together side by side.

As Dad ascended the stairs in my two-story townhouse and arrived at the second floor landing, he looked into the large floor-to-ceiling mirror somewhat puzzled and said, “Who is that?” For a minute I wondered if he meant me because he and I were walking up the stairs together side by side. But as I observed him staring into the mirror, it was clear that he was referring to himself. I answered, “*That’s you, Dad!*” We both snickered a bit and walked on to my exercise room.

I had been more focused on his physical health when in fact his mental health was at greater risk. I was actually stunned that he hadn’t recognized himself in the mirror. I know we make jokes about not recognizing ourselves in the morning when we get up, or when we’re sick, or have a bad hair day. This was different. He had actually looked into the mirror and asked, “Who is that?”

This is a poignant example of the devastating progression of **Alzheimer’s Disease** – herein referred to as AD – which actually robs one of their identity and then takes them from you. Think about it: AD steals the memory, literally taking the identity from the mind.

My preparation and research to write *Stolen* uncovered that growing numbers of people are becoming fearful of AD even more so than other incapacitating debilities such as cancer and heart disease. Why? Because at least you know who you are if you suffer with any one of the other diseases and there are treatments for many of them. Devastating afflictions such as HIV/AIDS have treatments now that allow the stricken to live long, close to normal lives, but AD has no cure - and treatment for its symptoms remains minimal at best, even though the disease was identified over a century ago. It has only been within the last 25 to 30 years that AD has become of major interest to the medical field because Alzheimer's is identified as the most common cause of dementia.

One major problem is that what causes this invasive disease, which damages and kills brain cells, remains relatively unknown. Although AD is associated with aging, it is not a part of normal aging. If you are not educated to look for indicators, you and your loved one can unknowingly be robbed of valuable quality time together. My brother and I were guilty of not knowing and did not recognize the early AD-related indicators that our father began exhibiting. The fact remains, however, that even if we did, the prognosis of AD is that there is no curing it. We may have been able to curtail the progression of the symptoms of the disease, but we would not have been able to stop it then any more than we can now. Once we were informed of Dad's illness, we knew that we had to take steps to manage his well-being. So our pursuit has always been to provide Dad with the best care we can afford.

A primary factor in establishing the best plan of care is the awareness that one of the greatest responsibilities and contributions to a loved one's sense of well-being is how we relate to them. We learned to control our reactions to statements and behaviors that at times seemed bizarre, such as Dad looking at himself in the mirror and asking, "Who is that?"

Imagine, if you can how it must feel not to recognize yourself, or to feel lost in your own home? Imagine also people talking to you

as though they know you well, but in your mind you've never seen them before or there is no history? When that happens to Dad, he looks so perplexed. I simply tell him, "The person who just smiled or spoke to you knows you, but you just don't remember them." Our dad has even asked my brother and me our names. We simply tell him our names in a very pleasant and unassuming way. It's important that we don't respond in a way that disturbs the patient even more than they are or shame and embarrass them.

We don't use the "AD" word around my father, either. We feel as though he really wouldn't understand the explanation involving *plaque and tangle buildup* in the brain that is robbing him of his memory and will ultimately debilitate his body to the point of death. To explain it would cause him mental anguish that would impact him in the moment and who knows how else. We do not want to take the risk of its effect causing added stress and irreparable emotional and mental damage. More specifically, to tell the AD patient that they have AD can conjure up fear or preconceived notions about the disease that may be negative. It could possibly escalate their sense of loss of independence, helplessness and more. We simply tell our father that his memory is failing him due to his age, and it's going to get worse, but that we are here for him. We reassure him that he is well taken care of and tell him to relax because there's nothing to worry about. We believe referring to it, as a serious memory problem that often comes with aging, rather than a fatal disease that will steal his identity, is more hopeful to a 93-year-old man.

Ironically, though, even if we told our father that he had AD, he wouldn't understand it or remember what we told him. In fact, does anyone really understand it? Yet the possibility is that at that moment when reality is shared; it *may* cause irreparable emotional damage, and for that reason it's simply not worth it. It's clear that there is much to learn and understand about Alzheimer's. Our journey with our father, which is captured on the following pages, has revealed much, confirmed some, and raised questions about what, why, who, and how regarding Alzheimer's Disease.

INTRODUCTION



S*tolen* is about the personal experience and the emotional turmoil that primary caregivers are exposed to, and the impact of the experience when they decide to provide in-home-care services to their loved one(s) diagnosed with AD. It chronicles the journey of my brother and me seeking to honor our father's wish to remain in his home. That has become our goal while we also ensure that he receives quality care. We wanted to promise our dad that he would remain in his home for the duration of the illness. However, I learned from my research not to make promises because no one can predict future circumstances.

My brother and I are Baby Boomers who pursued the American Dream and as a result have experienced some modicum of success, reaping the rewards afforded to those who embrace middle class values. I am the eldest. We grew up in Los Angeles and enjoyed the benefits of our parents' middle-class lifestyle, which they provided us. Most important are the middle-class values: a college education, a work ethic, self-respect, respect for others, especially our parents and elders, love of God, and overall an appreciation for our family, home, community, and country. My brother is married, with children and grandchildren. He retired as a captain from the fire department. I am divorced, a retired social worker, daughter, sister, sister-in-law, and an aunt. Although we are currently retired from the daily responsibilities of a job, we are not retired from life.

We have embraced our roles as primary caregiver to our father, and have pressed forward with our face diligently to the

wind to accomplish our major goal of providing Dad with quality care in his home.

It is the financial perils and maneuverings of in-home-care-givers, also known as in-home-care-providers and independent caregivers that has been the most challenging. It is a phenomena experienced by many other Baby Boomers who share this dilemma. The challenges that abound center primarily on the quality of care, the cost of quality care, the lack of education, and quality training for in-home-caregivers and primary caregivers in caring for AD patients. Although quality care should be available for all illnesses, *this book focuses on the required concern for and specific care of AD patients.*

I know that the term *quality of care* has become a generic phrase and used loosely, almost like a cliché in healthcare. However for our purposes, in *Stolen*, the definition of “quality of care” means: 1) Learning what makes our dad feel happy or content; and 2) Creating a supportive environment, which includes caregivers who must be in relationship with and connected to Dad’s life in supportive ways. Emphasis for us is on the comfort and well-being of Dad. We sincerely believe and continue to witness that emotional and relational well-being can be enhanced despite the progression of AD.

THE WHY

The rude awakening and impact of AD on our father and our family was an inspiration for this book. Our dad’s memory and ability to recognize familiar and intimate people, places, and things have been stolen. Unlike other catastrophic diseases, a person with AD is actually robbed of their own sense of identity, their sense of self, and they are unable to recall their past. Even more foreboding is that oftentimes they are unable to remember any misgivings or abuse afflicted upon them or around them by an unscrupulous caregiver. There is no past, no future, and the present is fleeting for them. For an AD patient, it’s all about the *now*! Imagine that!

You may have a great conversation with one who suffers from AD one minute and in the very next they cannot recall it. It can be baffling, and heartbreaking. They are not able to inform you about the most recent past, therefore they cannot account for events or the experience of their day. In other words, they cannot share what they do not remember. As primary caregivers, we have the daunting task of hiring a live-in-caregiver and leaving our dad literally with a complete stranger who is in total control while he is in their care. In addition, the overall lack of awareness about this disease – that it may become the leading cause of death in the next 30 years due to the complications it causes in the body – is startling.

Stolen was written to increase your awareness, not to alarm you. Because of our initial experiences of trying to provide what we thought was quality care for Dad, I now realize that it was a rather reckless and ambitious initial endeavor. I currently believe that it is not wise to assume a caregiver role for an AD patient without knowledge and information or assistance from a caregiver who has in-home-care training and experience with AD patients.

I prefer to refer to people afflicted with AD as patients throughout *Stolen* because AD is an illness. This opinion is not widely accepted. Some people think that it is patronizing. I disagree. We refer to Dad as a patient, but we don't treat him like one. That is to say, we do not treat him like an invalid.

Interestingly, many professional caregivers who call us seeking a job say they are looking for a patient for whom they will provide care. In my opinion, it feels more heartfelt to hear the reference to a patient rather than, "I'm looking for *a job* or *a client*." It is also a more accurate description of the compassionate relationship between the individual diagnosed with AD and their caregiver that we desire. Thus, this book is not about the efficacy of the medical field, nor the technical terms and jargons associated with AD, which can vary from one clinician to another. This book beckons you to take a closer look at what quality care means to the patient. Hopefully, this chronicle of our experience will also make you ask yourself, "What would

quality care look like for me if I were afflicted with this devastating disease?" and given the current economic conditions in the United States, "How would I pay for the quality care that I desire?"

HOW DOES THIS BOOK DIFFER FROM OTHERS ABOUT AD?

Stolen is unlike any other book on the market about caring for AD patients, many of which I've read. Our story challenges the quality of care provided and the high cost of in-home care, much of which is mediocre, for AD patients living in their homes. Some of the mediocrity is due to the lack of education and training on the disease.

Sadly, I've also discovered that there is a lack of patience and compassion in some caregivers for the AD patient. I believe that more hands-on-training and edification about this disease will result in more AD patients remaining safely in their homes or in homes with relatives and loved ones for longer periods of time, if they can afford it! *Stolen* not only documents the experiences we've had and the challenges that we've faced, but also presents practical, tangible solutions to the ongoing situations and problems you may confront as a primary caregiver. To assist readers in understanding our perspective of quality care, we have created Edu-illustrations. These are actual visual renderings complimented by narratives on handling some AD behaviors and cognitive changes. This book presents real-life characterizations of AD via illustrations primarily based on my father's experiences that are common challenges to many AD patients. The suggestions and recommendations in the Edu-illustrations are actually the interventions we've learned and have used successfully to defuse and mitigate difficult situations with our dad.

Ultimately, in *Stolen*, there is a critical look at the definition of a caregiver and a humanitarian call for caregivers to stop looking for a job and to start looking for a patient that they are willing to be in relationship with while caring for them. In addition, this book offers several creative suggestions for paying for quality care, which unfortunately can be very expensive. All of this is written from the perspective that AD is fast becoming one of the most notorious

thieves in the world. It literally robs the patient of everything that makes him or her who they are while kidnapping the patient and holding them hostage in their own bodies thus essentially robbing their family of their loved one as they once knew them to be. Further AD can drain the primary caregiver of their time, health, and financial resources if the knowledge of how to manage it is absent.

Stolen is about the impact of the disease on the AD patient, the robbery and loss that occurs in their brain that manifests in their daily life; the contribution primary caregivers and family members make to the patient's sense of loss; and the thievery and simultaneous robbery perpetrated upon the primary caregiver by the loss of their loved one, their time, their resources and sometimes their own health and well-being in providing care for the AD patient. In addition, there are the unfortunate circumstances in which unscrupulous family members and in-home-caregivers actually steal personal items and possessions from the patient, as well as rob the patient's sense of well-being due to lack of integrity and/or education and training about the disease.

Finally, it's the story of two people, perhaps like you, who are finding their way through and managing the care of a devastating disease and finding solitude in their effort to provide quality care to their loved one whose life is being robbed by AD. It's about how you can do the same for your loved one. *Stolen* is a chronicle of *their* journey. It is informative, instructive, entertaining, solution-based, and will challenge your future outlook on this disease.

CHAPTER 1

SO YOU THINK YOU KNOW ABOUT ALZHEIMER'S DISEASE



Did you know that AD is an insidious thief? It is an equal opportunity burglar. It is not a respecter of intelligence, status, wealth, race, color, creed, gender or religion. AD has stolen from presidents and princes. It has stolen from the rich, the famous and notable individuals such as the Kennedy family. It has robbed from scholars, movie stars and other celebrities, from all races and ethnicities. In the United States, projections indicate the African-American and Hispanic populations are diagnosed with AD at twice the rate of Caucasians. However, all classes of people – poor, middle-class, rich and the super-rich – continue to be robbed by this disease.

Whatever your financial status may be, the rude awakening is that it may diminish when you're looking at caring for yourself or a loved one in our current healthcare system. In fact, our middle class is currently what Rev. Dr. Martin Luther King in the 1960s referred to as the "working poor". Beware, because *AD, thief extraordinaire*, has the capability of wiping out retirements and inheritances, dissipating healthcare plans, decimating earnings and wreaking havoc on family relationships. Rather than being in denial, I recommend that you and your family members begin thinking and talking now about how you would deal with this brain invasion if it showed its ugly face in your family.

Consider if you will that there were a rash of burglaries in your neighborhood, wouldn't you address how to secure your home? Wouldn't you start to read, inquire and research ways to protect yourself and your family? First and foremost, wouldn't you try to prevent the break-in? Second, wouldn't you probably make a plan about what to do if the robbery occurred? Finally, wouldn't you want to catch that thief?

I suspect that you would report the invasion to the authorities. They in turn would pursue and seek to apprehend the robbers. They would continue to investigate and interrogate various suspects in order to hunt down and arrest the guilty thief or thieves. It's the same case with AD – it is a thief. However, there are other thieves with a similar *modus operandi* emulating some of the same symptoms.

AD is only one type of dementia. Dementia is not a diagnosis. It is a symptom and generally described as an impairment in or loss of mental powers. Catching the right thief (the right type of dementia) requires an intense, precise investigation, which includes comprehensive medical and cognitive evaluations. It's comparative to the forensic tests used to identify an actual thief. Many clinicians consider AD a disease of elimination. The point is that accurately identifying the right thief is synonymous with making an accurate diagnosis by distinguishing and differentiating AD from other dementias. An accurate diagnosis is the key!

Your first act must be to arm yourself with information to improve your knowledge of AD and then begin to dialog with those more knowledgeable than you about the potential risk of a brain invasion caused by AD.

Next, begin to share and discuss with other family members and invite them to do the same. Adult children must take the step to talk about it to their Baby Boomer parents. Baby Boomers must muster up the courage to talk about it to their geriatric parents. It's a difficult subject to broach.

Baby Boomers, born roughly between 1946 and 1964, are in a vulnerable position. Many of them are also referred to as “the sandwich generation” because they are still caring for their own child(ren) while also caring for their parents. This places them in the middle between the two – their children and their parents, both with demanding needs. By 2020, it is estimated that one-third of Americans will be responsible for in-home-care of an elderly parent. This brain disease could devastate you and your family if you don’t start talking and making plans now about how to care for a loved one, as well as how to finance the care. For example, long-term care insurance is an option in planning for emergencies, which should be implemented sooner rather than later in life. This book is the beginning of the information you will need to read in order to prepare for the possibility of a brain invasion by AD. It is meant to lay the groundwork and point you in the right direction. A wise person once told me “first you learn to read, then you read to learn.”

WHAT YOU SHOULD KNOW VERSUS WHAT YOU KNOW

Stolen is intended to be a lifeline to you. Many of the innuendos about AD I learned on the job and in real time while my brother and I cared for our father. I literally enrolled in the first AD conference I could find as soon as Dad was diagnosed, and afterwards shared the information with my brother so that we would be on the same page. However, at that time I really didn’t grasp the complexity, the unpredictability, how the impact of the disease varies from individual to individual, and how it robs not only the memory, but one’s cognitive abilities as well. I suspect that many of you have probably picked up tidbits of information about AD from random sources and may think that you know all that you need to know about it. There’s a strong possibility that you may *not*! So I’ve developed a short AD True/False “*Pop Quiz*” to provide you with some insight in understanding and managing this difficult disease.

In retrospect, I wish I would have read more on the disease and people’s personal experiences on managing AD, rather than focusing on clinical issues of the disease. I want to encourage you to

care for your loved one as they desire, whether it's in their home or yours. If remaining in their home or yours is desired and you genuinely want the same for them, do not be unduly alarmed by all the terrifying stories you hear and read about AD.

I have taken this time to carefully share with you our experience with the express purpose of providing insight that might enlighten your understanding and broaden your perspective of Alzheimer's and its impact on the patient, the in-home-caregiver, and you.

Let me make it perfectly clear. The disease is very demanding, yet if you remain open, quality care for the AD patient can be a wonderful blessing to both of you when you've done your homework on the disease. The Internet is a wonderful source of information, as well as the local AD Associations. It doesn't matter whether you are the primary caregiver or an in-home-caregiver. Comprehending the ramifications of these questions and understanding the answers I have developed will help minimize some of the anxiety and stress associated with the disease for you and the patient. The answers are discussed in depth throughout the following pages. There are also processes, techniques and illustrations to help you gain greater insight to visualize and internalize the AD patient's and the caregiver's feelings and challenges.

AD "POP QUIZ"

Take the following quiz by circling either the appropriate T (true) or F (false) answer to the questions one through twelve. Save your answers and take the quiz again upon completion of the book and compare your answers. The answers and their corresponding pages are revealed at the back of the book. Good luck, the answers may be very revealing to you!

1. "Love is enough" in providing quality care for AD patients
___T/F___
2. AD is a form of dementia. ___T/F___

3. Caregivers should not try to question, reason, or chastise AD patients, if necessary, about their behaviors. ____T/F____
4. Telling the AD patient the truth about their illness is the best principle for managing AD behavior. ____T/F____
5. AD is reversible. ____T/F____
6. Most paid or independent caregivers are educated and trained to provide quality care to AD patients. ____T/F____
7. It is always appropriate to give a paid-caregiver a two-week termination notice. ____T/F____
8. Sexual harassment is a valid allegation for sexually inappropriate statements or actions of AD patients. ____T/F____
9. Normal aging involves a serious decline in mood, cognition, and functional behavior. ____T/F____
10. To have to stop driving is reportedly one of the most threatening activities related to loss of independence to an AD patient. ____T/F____
11. Sundowning is a natural progression of AD for all patients. ____T/F____
12. Most paid caregivers report that caregiving was their first career option. ____T/F____

CHAPTER 2

DEMYSTIFYING THE MYTHS



Many people think that AD is the same as what was referred to as *senility* back in the day. I know that I always thought senility was a natural condition of old age. I reasoned that it was a natural course of aging, which resulted in a weakness or impairment of the mental faculties that affect the mind and body.

Contrary to this opinion, I have learned that it is now widely accepted by many doctors that senility is not a normal part of aging. In fact, many use the two words – senility and Alzheimer’s – interchangeably. AD, hence senility, is a degenerative disorder causing dementia. It is currently not reversible. AD is not a normal part of aging. As mentioned earlier, Alzheimer’s is only one cause of dementia. Now you’re probably asking, “So what is dementia?”

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p. Dementia is a general term that describes a progressive disease that has a set of symptoms related to deterioration in thinking skills. Some typical dementia symptoms include gradual memory loss, judgment difficulties, disorientation, and difficulty in learning new tasks or performing old ones, and the loss of language skills. Refer to Appendix No. 2 for a brief list and definition of other dementias that have symptoms similar to AD.

To my surprise, most doctors do not consider dementia a mental illness, although dementia can include symptoms similar to a

mental illness, such as social inappropriateness, anxiety, or compulsive behavior. Mental illness is *psychological*. Dementia is a brain disease, meaning it is *neurological*. It is widely accepted that AD mainly affects the area of the brain involving memory, speech, and other higher functions.

According to the National Alzheimer's Association, AD has 10 warning signs:

- 1. *Loss of memory***
- 2. *Difficulty performing familiar tasks***
- 3. *Problems with language***
- 4. *Disorientation to time and place***
- 5. *Poor or declining judgment***
- 6. *Problems with abstract thinking***
- 7. *Misplacing things***
- 8. *Changes in mood and behavior***
- 9. *Changes in personality***
- 10. *Loss of initiative***

The first warning sign – loss of memory – is one of the most notable signs of AD that people recognize, and ironically it is also the most ignored one in recognizing the disease at its onset. There is a difference between mild forgetfulness and serious memory problems. Some examples of mild forgetfulness are:

- It may take longer to learn new things.
- It may take longer to remember familiar names and words, or to locate misplaced items like keys or glasses.

On the other hand, some of the examples of serious memory problems are:

- Asking the same questions over and over again (once answer is provided).
- Becoming lost in places you know well.
- Not being able to follow directions.

- Getting very confused about time, people, and places.
- Not taking care of yourself – eating poorly, not bathing, or being safe (as a result of not being able to remember to do it).

To complicate matters, some of the causes of serious memory problems that mimic AD are:

- Bad reaction to certain medicines
- Depression
- Dehydration
- Minor head injuries
- Thyroid problems
- Vitamins or minerals deficiency
- Poor diet (a lack of healthy foods)

Complicating things even further is the fact that some emotional problems experienced by many older people such as feeling sad, lonely, stressed or extremely bored can also cause confusion and forgetfulness. So, as you can see, a diagnosis of AD is not easy and AD is definitely not simply a memory problem, as many may assume. Now you can see why specialized training and awareness is required. Just being aware of the 10 warning signs can give you a heads up and make a huge difference in doing the right thing for yourself or loved one.

IGNORANCE IS NOT BLISS

If you are concerned about your health as it relates to your memory or that of your loved one, it is mandatory to get a medical evaluation to determine whether an AD assessment is appropriate. To my knowledge, there is no single type of doctor that specializes in diagnosing and treating AD or memory symptoms.

First, I suggest that you consult your doctor, a general practitioner. Many oversee the diagnostic process, but they will refer to a specialist. Some specialists are neurologists who specialize in diseases of the brain and nervous system; psychiatrists who

specialize in disorders that affect mood or the way the mind works; psychologists with special training in testing memory and other mental functions; perhaps, a geriatrician who specializes in working with the elderly. Some sources estimate that a skilled physician with training can determine that a person has dementia, but will probably have difficulty determining the exact cause. It is widely accepted that these specialists can make a clinical diagnosis after conducting numerous tests and a thorough family and health assessment. These diagnoses are reportedly 80-90 percent accurate. Dr. Peng

I do believe that in the not-too-distant future, general practitioners will have to be trained to accurately diagnose patients who appear to have some form of dementia because of the sheer number of projected cases in the next 10 to 15 years. A comprehensive medical evaluation should include a complete medical history, including serious illnesses, hospitalizations, family members' illnesses and causes of death, medications, and a social history that includes education, military service, and so on. For example, neurologists look for possible changes in the brain through Magnetic Resonance Imaging (MRI). Doctors and clinicians should investigate medications used, nutrition, alcohol intake, metabolic disturbances, depression, and other possible causes of dementia. Some medical colleges can be a resource for diagnostic testing for AD.

Stolen claims, irrefutably, that recognition of the AD warning signs and accurate diagnosis are the keys to being ahead of the game. In addition, knowing why or whether you or a loved one may be at risk or not for the disease places you in the position of power rather than one of a victim, because knowledge is power.

Are You At Risk For Alzheimer's? 12 Questions **Paula Spencer Scott, Caring.com senior editor**

Although there is increasing support that certain basic lifestyle changes may influence the disease in some people, the exact cause of Alzheimer's Disease isn't yet understood. Alzheimer's is a progressive neurodegenerative brain disorder: normal brain cell

function is gradually destroyed, leading to irreversible declines in memory, cognition, and behavior. But what causes things to go awry remains unknown. It may be that Alzheimer's has several causes or that the interplay between genetic makeup and certain risk factors determines who's affected. The following questions are based on some of the widely accepted risk factors for Alzheimer's. See how many apply to you, to assess your risk of eventually developing the disease, or how they apply to someone you may be caring for.

1. How old are you?

At lower risk: Under age 70

At higher risk: Over age 85

Why age matters: Age is the most significant established risk factor for Alzheimer's. One in seven people over age 71 has some form of dementia, and 2.4 million of these have Alzheimer's, according to the latest National Institutes of Health data. The percentage of people with Alzheimer's rises from just 2.3 percent of those ages 71 to 79 to 18 percent of those ages 80 to 89, and 29.7 percent of those 90 or older. Some estimates say as many as half of all people over age 85 have Alzheimer's Disease.

The total number of people with the disease doubles with every five-year age jump after age 65.

2. Male or female?

At lower risk: Men

At higher risk: Women

Why gender matters: Because women live longer than men, on average, and Alzheimer's Disease risk rises with age, more women than men develop it. In addition, some research indicates that a lack of estrogen after menopause may contribute to the fact that, overall, slightly more women are affected. Taking hormone-replacement therapy has not been shown to protect against Alzheimer's.

Vascular dementia is more common in men than women, probably because more men develop contributing factors such as hypertension and vascular problems.

3. Have any parents or siblings had Alzheimer's?

At lower risk: No family history or known genetic predisposition

At higher risk: A family history or known genetic predisposition

Why family history matters: People with a family history of Alzheimer's are more likely to develop the disease. The risk is thought to rise with each relative who had it.

It's unknown, though, exactly how much of this association is due to genetic factors and how much is due to shared lifestyle factors. Most experts believe that some combination of the two is responsible. Even when an immediate family member has the disease, however, your increased risk is only slightly higher than if your family had no history of dementia.

Up to 80 percent of Alzheimer's risk may have a genetic component, according to a 2006 study of more than 12,000 Swedish twin sets – a greater influence than was previously thought. But having a relative with the disease does not doom a person to a similar fate; even among identical twins, when one male twin had it, almost half of the time the other twin did not. (Among female twins, the other twin developed Alzheimer's 60 percent of the time, a difference researchers attributed to the fact that women generally live longer than men.) If Alzheimer's were solely genetic, both twins would have developed the disease, and at about the same time.

So far, only two types of genetic tests for Alzheimer's exist, and neither of these blood tests is currently recommended for routine use.

One kind of genetic test identifies a person's risk of developing Alzheimer's Disease, but doesn't guarantee whether or not they'll develop the condition. Everyone inherits a form of the apolipoprotein (APOE) gene from each parent. Apolipoprotein helps carry cholesterol in the blood. Its three most common forms are APOE-e2, APOE-e3, and APOE-e4. Those who have two copies of APOE-e4 seem to be at the highest risk of getting Alzheimer's and of developing symptoms earlier in life. Having one copy of APOE-e4 also elevates the risk. Only about 15 percent of people carry the APOE-e4 form.

It's thought that APOE is only one of many genes involved in the disease process. For instance, while it's considered a strong risk factor, the APOE-e4 gene shows up in only about 40 percent of all people with Alzheimer's Disease. Identifying other genes that may be involved is a focus of ongoing research.

The National Institute on Aging is conducting an Alzheimer's Disease Genetics Study, which is currently recruiting sibling pairs. These pairs must both have developed Alzheimer's after age 60 and must have a third family member with or without the disease who's willing to undergo cognitive tests and blood sampling.

A second type of existing genetic test for Alzheimer's Disease can predict with certainty who develops one rare form of the disease. This is early-onset familial Alzheimer's Disease, which strikes between the ages of 30 and 65 and stretches through multiple generations. It accounts for less than five percent of all cases.

4. Is there tobacco use?

At lower risk: Nonsmokers, former smokers

At higher risk: Current smokers

Why smoking matters: Evidence is growing that smoking raises the risk of developing Alzheimer's Disease by as much as 50 percent. In late 2007, Dutch researchers who tracked almost

7,000 people age 55 or older for seven years reported that current smokers were more likely to develop dementia than people who had never smoked or had quit. Interestingly, the effect was more pronounced for people who did (not) have the APOE-e4 gene (the type known to be most vulnerable to the disease). Smoking didn't raise the already elevated risk of Alzheimer's in those who had the APOE-e4 gene.

It's thought that smoking damages the cardiovascular system and causes oxidative stress, both conditions that are associated with Alzheimer's.

You may have heard that smoking protects against dementia—which is a myth. This persistent idea grew out of flawed studies and because fewer people with Alzheimer's were smokers. But in fact, smokers tend to have shorter life spans and are less likely to live to the advanced ages at which Alzheimer's most often strikes. ✕

5. Do you have diabetes?

At lower risk: No history of diabetes

At higher risk: Those with type 2 diabetes

Why diabetes matters: People with type 2 diabetes have at least double the risk of developing Alzheimer's compared with people without diabetes. The risk was 65 percent higher for diabetics in 2006 data from the ongoing Religious Orders Study of priests and nuns. Some studies have found that the higher the blood sugar levels, the higher the dementia risk.

The mechanics behind the Alzheimer's-diabetes link aren't certain, but this is an area of intensive research. The leading explanations:

High blood sugar may cause vascular problems. It's known that diabetes can cause cardiovascular problems and strokes; reduced blood flow to the brain may cause small-vessel damage

there that leads to vascular dementia (a type of dementia that can appear with Alzheimer's).

Insulin resistance leads to inflammation that can damage the brain. Insulin resistance occurs in diabetics when their cells can't use insulin properly to move glucose from the blood to be used for cell energy. The pancreas then makes extra insulin to compensate, which builds up in the blood and creates inflammation, which damages brain cells.

Insulin resistance in the brain disrupts the proper formation of neuron connections. The autopsied brains of people with Alzheimer's always show amyloid plaques, clumps of the protein beta amyloid, which ruin brain cell connections. It's been discovered that this substance destroys the brain cells' receptors for insulin, which is used by the brain to make new memories. This results in dementia and memory loss.

As evidence of a clear biochemical link between the two conditions grows more compelling, some are calling Alzheimer's Disease "type 3 diabetes."

There's also a likely genetic link between diabetes and Alzheimer's. People with diabetes who also have the APOE-e4 gene (the type that places a carrier at highest risk for Alzheimer's) were two-and-a-half times more likely to develop the disease, according to a 2008 National Institute on Aging study.


6. Is there a history of being overweight?

At lower risk: Low BMI in midlife

At higher risk: Overweight or obese in midlife

Why weight matters: Being overweight or obese as measured by body mass index is well associated with an increased risk of developing dementia. Men with the leanest body mass index (BMI) in their late 40s and mid-50s were the least likely to develop Alzheimer's in a 20-year study of more than 7,000 Swedes; those

who were heaviest were most likely. This same study also later found that women who were overweight at 70 were more likely to develop Alzheimer's in the next 10 to 18 years.

People who are overweight are more likely to have related health problems that are also linked to Alzheimer's, such as hypertension, high blood pressure, cardiovascular disease, and diabetes. 

A related risk factor is if someone was previously overweight but has had unexplained weight loss recently. Weight loss associated with dementia may begin six to 10 years before other symptoms become obvious. Research isn't clear whether this is because of declining ability to prepare meals or is a function of the disease process.

7. Has there been a serious head injury?

At lower risk: No injury

At higher risk: Prior head injury, especially after age 50

Why head injury matters: Prior head injury – even years earlier – is linked with a greater risk of developing Alzheimer's, though it's not clear why. That's not to say that any youthful bump will lead to Alzheimer's. The injury itself isn't thought to directly ^{not} cause the disease, although it may hasten the process. But the more severe the trauma, the greater the risk of developing Alzheimer's, according to a large study of World War II veterans. The most concerning are thought to be falls with head injuries that occur later in life.

8. Are you a college graduate?

At lower risk: Higher education level

At higher risk: Lower education level

Why education matters: People with lower education levels are more often affected by Alzheimer's Disease. Researchers theorize that longer education helps the brain develop stronger, denser, more complex connections between brain cells, creating

more cognitive reserve. This positions the brain to be better able to withstand the abnormal stresses associated with Alzheimer's Disease and compensate for the changes that occur.

9. Do you consume a balanced, low-fat, vitamin-rich diet?

At lower risk: Heart-healthy diet rich in antioxidants

At higher risk: Eating high-fat foods and an unbalanced diet

Why diet matters: Although there's no "Alzheimer's-prevention diet," a growing body of research indicates that nutrition influences brain health and may protect against or postpone cognitive decline. Specifically, your overall risk of Alzheimer's may be lower if you consume:

B vitamins: People who are foliate (B-9) deficient may run triple the risk of developing dementia, according to recent South Korean data. Previous research showed vitamin B-12 to be protective.

Vitamin E: Those who consume the highest dietary amounts of this antioxidant have a lower incidence of Alzheimer's. Vitamin E supplements have not been shown to have the same protective effect.

Vitamin C: Another antioxidant, vitamin C, seems to have a protective effect in certain people, though possibly only in dietary form. Antioxidants counter the effects of oxidative stress, which is linked to nerve cell damage and death. Over-the-counter vitamin C supplements did not reduce Alzheimer's risk in a recent study of 2,969 people 65 and older.

A heart-healthy diet: People who consume a generally balanced diet that avoids too much fat and includes complex carbohydrates are less likely to develop conditions that are Alzheimer's risks, including obesity, diabetes, and cardiovascular disease.

10. Do you exercise regularly?

At lower risk: Active lifestyle

At higher risk: Sedentary lifestyle

Why exercise matters: Regular exercise reduced the risk of dementia by as much as 40 percent in a 2006 study of nearly 2,000 people age 65 and older. This was the first study to factor in one's pre-existing physical condition. And those most frail at the start of the study showed the greatest protection against dementia if they exercised. The threshold that made a difference: physical activity for at least 15 minutes, three times a week. Exercise both lowers the risk of obesity and cardiovascular conditions linked to Alzheimer's and reduces the risk of developing dementia.

Previous research has shown that the variety of activity engaged in is more important than the intensity of a workout, when it comes to providing brain benefits. (Variety of workouts had no benefit, though, to those with the APOE-e4 gene variation most commonly associated with Alzheimer's.)

11. Do you engage in mentally stimulating activities?

At lower risk: Varied, frequent "brain workouts"

At higher risk: Lack of mental stimulation

Why mental stimulation matters: Just as physical activity exercises the body, "cognitive activity" exercises the brain. Numerous studies now support the "use it or lose it" idea that mental workouts lower the risk of dementia. For example, participants in the Religious Orders Study who attended museums, worked puzzles, and read newspapers were 47 percent less likely to develop Alzheimer's after four years than those who did such activities less frequently.

Brain-stretching activities can't prevent Alzheimer's, but they help the brain better withstand the physical changes associated with it. What's key: The stimulation should be ongoing.

12. Is there social stimulation?

At lower risk: Social engagement

At higher risk: Social isolation and loneliness

Why social stimulation matters: Isolation is a risk factor for developing dementia, probably because there's less opportunity for mental stimulation. But a surprising 2007 study also found that people who were around others but felt lonely (emotional isolation) were also at higher risk for Alzheimer's. This sense of loneliness wasn't a result of the disease (as is often the case with depression).

PLAQUES AND TANGLES

To my disbelief, AD was first identified over a century ago by a German neurologist whose name was Alois Alzheimer. In 1906 Alzheimer examined the brain of a deceased 51-year-old woman whose early-onset dementia he had been following for many years. The autopsy of this woman revealed that nerve-cell fibers in her brain were entwined in what he called "neurofibrillary tangles." He named the areas of marked deterioration "plaques." He observed that as plaques and tangles accumulate, brain function deteriorates. To this day, these obscure tangles and plaques continue to be the markers of AD upon an autopsy, and not before.

The caveat about this obscure brain disease is that a brain autopsy after death is the only absolute sure way to determine if a person was diagnosed accurately with AD, which is alarming to many people. Scientists are working diligently to find other diagnostic procedures to accurately diagnose AD in the early stages of the disease.

AD appears to affect mainly the area of the brain involving memory, speech, and other high cognitive functions causing such problems as impairment of judgment, personality change, difficulty in learning, and loss of language and communication skills. It doesn't, however, affect brain areas relating to basic body functions such as breathing and circulation until vital organs and functions are compromised in the latter stages. Therefore, patients do not die

because of the disease itself, but because of the medical complications it causes in the body.

Although there is no definitive cure for AD, some studies have emerged identifying genetic connections, protein connections, foliate and aluminum connections, and environmental toxin connections to this disease. However, there appears to be a great deal of controversy about these studies. Because there is no cure or viable treatment for AD, early diagnosis is very important. There are however, popular medications available such as Aricept, Exelon, and Galantamine that can slow down the progression of the symptoms.

THE PERPLEXITY OF AD

Many doctors generally refer to some type of stage of AD, when they diagnose the disease, and when they discuss the progression. It was fascinating to learn that each stage may be as brief as one year or as long as ten years. There is a wide variation of symptoms from individual to individual. The constant refrain of many family members and caregivers is, “The most predictable part of AD is the unpredictability”.

I cannot reiterate enough that “change is the only constant” throughout the progression of AD. I can honestly say that it is simply mind-blowing and heart-wrenching to see your loved one go:

- from well-groomed to sloppy, unshaven, and disheveled;
- from well-spoken to having a complete loss of language;
- from sleeping well to experiencing insomnia;
- from being happy to depressed;
- from being outgoing to being withdrawn;
- from being meek to being aggressive;
- from being independent to dependent;
- from being calm to being anxious;
- from having excellent recall to not recognizing familiar faces and places;
- from having a good sense of direction to getting lost;
- from being decisive to being in-decisive;

- from being focused to having difficulty concentrating;
- from possessing good writing skills to being unable to write or sign their name;
- from enjoying reading to not being able to read;
- from being physically fit to experiencing a loss of motor skills;
- from having urine and bowel control to experiencing incontinence;
- from possessing impeccable manners to being socially inappropriate;
- from being orderly and organized to losing and misplacing items;
- from having a good memory to no memory at all;
- from demonstrating intellect to no comprehension;
- from being an eloquent speaker to a rambling, garbled speaker;
- from establishing good eye contact to casting a downward gaze;
- from having a healthy appetite to forgetting to eat and eventually how to eat;
- from walking with a good gait to a shuffling pace and ultimately not remembering how to walk;
- and from the ability to take care of one's daily living activities to total dependent care.

Of all these changes, I think the most devastating one for caregivers, particularly primary caregivers, to experience is the inability of their AD patient to recognize them. Imagine that your mother or father, husband or wife, brother or sister just doesn't know you from the next person. The best advice is to do the due diligence and research so that you will be prepared, because it doesn't get better. You need to know what to expect ultimately. And most importantly, you must learn not to take any of their erratic behavior personally.

I know the thought of all these potential changes that could manifest in your AD patient can feel overwhelming, so keep in mind that your patient may experience some, but not all, of these symptoms.

If they do experience a significant number of these symptoms, it is manageable with good, creative caregiving that can be provided for in the home or a familiar environment given that there are no serious behavior problems. I believe that it is most beneficial- almost mandatory- for a primary caregiver to have the support, the knowledge, and experience of a trained in-home-caregiver to help provide quality care to an AD patient because of the mysteriousness of this mentally, emotionally, and physically taxing disease.

Case in point, there was one occasion our dad experienced some acute changes physically and cognitively within a four-hour period. I was ready to transport him to the emergency room, but the caregiver kept insisting that Dad really didn't need to go to the hospital – that he just needed to rest. Imagine if you will, in that short span of four hours, our dad went from being strong, ambulatory, verbal, and alert to weak, requiring assistance with walking and eating, uttering incoherent speech, and becoming very lethargic. It was distressing to see him in that state, but it was our confidence in the caregiver's character, professionalism, and her overall experience that convinced my brother and me not to take Dad to the hospital. Instead, we decided to monitor him closely the remainder of that day, as suggested by the in-home-caregiver.

The next day he was back to being himself. He was walking independently with his walker. He was alert, speaking coherently and laughing. His voracious appetite had returned, and he was feeding himself. We were simply ecstatic to see him so revitalized. We could not help wondering what had happened to him the day before, and what triggered it. But most importantly, I was so grateful for the caregiver whose prior experience with AD patients calmed me down because I was definitely a hot mess that day.

It is these types of inexplicable episodes that terrify primary caregivers and inexperienced in-home-caregivers to the point of giving up; thereby, forcing primary caregivers to place their loved ones in some type of out-of-home facility, which oftentimes inadvertently steals even more of their independence. This is also even

more reason to have a skilled, trained and experienced AD caregiver. Many patients may be able to flourish more and for longer periods of time in their homes with the one-on-one attention and stimulation of a good caregiver, which is not always available in facilities. For those primary caregivers who need more support in order to keep their patients in their homes, in addition to in-home care services, there are adult day care centers or adult healthcare centers in many communities to assist primary caregivers with out-of-home services. Other alternatives are out-of-home-care facilities such as assisted living facilities, residential group homes and lastly, long term care in convalescent homes and nursing homes are available for many AD patients.

As you read *Stolen*, you will find that there is strong and convincing evidence that many AD patients may be able to flourish more in their homes and for longer periods with more knowledgeable primary caregivers and the assistance of trained compassionate in-home-caregivers.

CHAPTER 3

GENESIS



The saga for us began when we finally recognized the look of bewilderment in our dad's eyes and acknowledged the bewilderment that we too, were feeling.

"Stop staring at me with pity in your eyes" and "I'm doing the best I can," are the thoughts I am sure were going through my dad's head as my brother and I gawked at him unconsciously on a daily basis. "What's happening to Dad?" was our nonverbal communication to each other as our father gazed back at us. Our dad has AD and is loved very much by my brother and me. Now, we realize that the most loving and nurturing thing that we can do for him, is to try to control our reaction to his seemingly unusual behavior and cognitive changes due to the devastating effect of AD.

It is clear now that our stares, though unconscious by nature and definitely the result of concern, probably communicated something totally different to Dad – pity, embarrassment, shame, hopelessness, and bewilderment may have been a few interpretations of what our facial expressions conveyed. You may ask does it matter since he won't really remember. We currently understand and believe that it is in the moment where AD patients live that counts and can impact their sense of well-being, and possibly the progression of the disease. Dad may not be able to recall our puzzled gaping looks after

it is done, but the emotional impression experienced in the moment definitely affects his sense of well-being.

In the spring of 2003, my brother and I noticed that Dad was very lethargic and depressed. A man 6'2" was now bent over almost in half when he walked. He was unshaven and shabbily dressed most of the time. This was particularly alarming because he had always been well dressed and meticulous about his personal hygiene. Dad had taken pride in his image. He had been athletic and the picture of perfect health. The fact that his home was suddenly unkempt shocked us also. Our layman diagnosis was that Dad was suffering from grief. Our mother, and Dad's wife of 58 years, had died from leukemia the summer of 2000, leaving him alone in his home for the first time.

The novice that I was in this situation, I simply thought that Dad's home was too large for him to maintain, so I volunteered to take him to look at assisted living facilities. These are facilities that do not provide medical care or nursing. They do however provide a nice room, supervision, meals, activities, and assistance with tasks such as dressing, eating, and bathing. We visited one such facility, which has an excellent reputation in our community, and a long waiting list. It was a multi-purpose compound consisting of assisted living quarters, a skilled nursing facility quarter, and an AD quarter. The convenience of providing all the services one might eventually require on location was very inviting. After touring the facility, Dad commented that he thought the facilities were nice, but stated adamantly that he wanted to remain living in his own home. That was the end of the discussion and we returned to his home, where I dropped him off.

Dad's behavior continued to decline until we finally told him that he had a choice of staying in his home with part-time help or going to a nice facility to live. Our greatest concern was his safety. Bills were piling up. He was observed eating oatmeal out of a pot, and there were sightings of scorched pots in the kitchen sink. His gait was becoming more unbalanced, which always precipitates a

fall, and his personal appearance as well as his memory were more on the decline.

Dad really didn't want anyone in his home helping him except me or my brother. However, both of us were employed at the time and unable to provide the day-to-day care and supervision we thought he required. To accommodate his reluctance and the fact that he had been very independent, we persuaded him to allow a person to come into his home two to three days a week initially for four hours to prepare meals and do light house-cleaning. We felt that Dad could remain home alone at night. Begrudgingly, he agreed to the part-time assistance in his home. Initially it was three days a week; then it went to five days a week. Dad adjusted very well to the routine. However, a turning point occurred in 2004 that changed everything.

In January 2004, when Dad was 84, we took him to his HMO for an evaluation because we noticed that he couldn't recall important information; didn't know what day it was; and was neglecting his physical appearance. My brother and I requested his HMO to conduct an evaluation for dementia. After having a complete physical and taking a test called the Folstein Mini Mental Status Exam (hereafter referred to as MMSE) for cognitive and reasoning abilities, the HMO's assessment was that Dad had age-related memory loss. He was described as awake, alert, pleasant, and conversant. His score was 26/30. This meant he performed 26 of the tasks or answered questions appropriately, out of a total of 30.

In May 2004, we flew Dad to his granddaughter's graduation from Georgetown Law School in Washington, D.C. During that three-day turn-around trip, Dad became severely disorientated, confused, and demonstrated signs of anger and hostility we never witnessed before. We recognized that it was clearly a mistake to have flown Dad across the country.

In retrospect, I remember telling my brother a couple of days before the flight that I was concerned about Dad's well-being because I had observed a shift in his demeanor. However, I was

dissuaded from doing anything by the fact that the airline tickets and hotel accommodations had already been purchased. Nevertheless, the reason for Dad going to D.C. to attend his granddaughter's graduation had been in vain, as neither Dad nor I were able to attend the graduation because of his state of mind.

I learned later that flying can have an adverse effect on AD patients, and apparently it had affected Dad. Upon returning home, I convinced our father to have a medical examination to determine what was going on with his memory and mental faculties. This time Dad's HMO conducted the MMSE in June 2004 and the score assigned him was 20/30, six points down from January. The HMO determined his cognitive and reasoning abilities had declined significantly enough to make driving unsafe for him. Dad was subsequently diagnosed with *Alzheimer's Disease*.

This was 2004, and back then we didn't know about the National Alzheimer's Association's 10 warning signs that were widely accepted in the medical field. Yet we clearly recognized some memory issues and odd behavior that concerned us, which turned out to be many of the warning signs for AD. This leads me to believe that the HMO missed the warning signs, relegating it to age-related memory loss in January 2004. I have read, after the fact of course, that this type of oversight could have occurred because Dad "presented" such good social skills, which can influence an inexperienced doctor. I have also considered the possibility that the AD progressed extremely fast during that six-month period, as well as the possibility that the flight hastened the progression.

Regardless, the geriatric doctor recommended the medication, Aricept, which was well tolerated by Dad. Surprisingly, it did appear to slow down the progression of his symptoms, and his daily living activities remained constant for a couple of years following. Still, I keep thinking that had we known more about AD, perhaps an earlier diagnosis would have made more of a difference. Perhaps we should have had Dad tested for AD when he exhibited what appeared to be behavior that was very different from his usual behavior.

However, I've learned since that if the patient or the caregiver can identify the loss of memory incidents as possible AD symptoms and get assessed and diagnosed at that time, the progression of the symptoms of the disease could possibly be slowed sooner with medications. In other words, an assessment and diagnosis (with an 80-90 percent accuracy rate) before the behavior changes set-in should be the objective in the Early Stage of AD. I only hope doctors become more aware of this practice and are trained accordingly, hence my emphasis on *AD-specific training* for primary caregivers, in-home-caregivers, nurses, as well as doctors.

In June 2005, we requested a MMSE evaluation and Dad's HMO determined there was no significant change since 2004. His score remained 20/30.

Another turning point occurred in January 2006. Dad had a serious gout attack affecting his left big toe that culminated with surgery. Miraculously, the doctors were able to save the toe. However, due to the length of time that Dad was bed-ridden in the hospital; he developed atrophy in his legs and lost the ability to walk. Subsequently, he had to be admitted to a skilled nursing facility for rehabilitation. In this facility, my brother and I noticed that Dad experienced a severe decline in mental and cognitive abilities, which we feared would continue to progress and would not be reversible if he remained there. We believed the mental decline we were observing was associated with the facility environment and not the disease, or his direct response to being in this facility and not in his own home. We also didn't know whether the general anesthesia Dad received for his gout surgery had anything to do with accelerating the downward spiral. In 2006, I didn't know whether there were any research studies or clinical trials involving general anesthesia and the effect on AD patients. However, I had an intuitive feeling that surgery involving anesthesia may exasperate the mental, emotional, cognitive skills and abilities of an AD patient.

It doesn't take a genius to realize that the brain is already vulnerable as a result of AD, which attacks brain cells. General anesthesia

during surgery tempers the brain to the extent that you cannot even remember the trauma and pain associated with a surgery. I really believe that the medical field and researchers need to take a closer look at the effect of general anesthesia on AD patients. I vowed to continue to research this matter.

Further, I believe the anesthesia in a patient's system, along with the trauma of being placed in a facility that is foreign to you: sharing a room with one or two strangers; being put in diapers; given a urinal to urinate in or having a catheter inserted; and lastly, having drugs administered to combat your confusion about being in the facility in the first place - all contributed to an extremely traumatic experience, coupled with the distressing symptoms of AD, for Dad. His extreme confusion, disorientation, and hostility were directed at me and my brother. We did witness that his independence and dignity were being undermined by the facility often, which did not allow him to walk or assist him to the restroom and resulted in him lying in his own urine until someone came to change him.

It was during this time that we observed that there was just an overall lack of physical and mental stimulation, as well. Nearly every time we visited Dad, which was daily, he was just sitting in bed, in a room with sparse light, and a television was always on. We believe that all of these factors had a negative impact on Dad's AD condition: first the anesthesia, and then the facility.

WELL-MEANING PRIMARY CAREGIVERS

I began to think about the number of times I had heard about well-meaning primary caregivers similar to us who placed their loved ones in a facility, whereupon the patient appeared to have given up and passed away. It occurred to me that for many patients being placed in a convalescent home, even rehabilitation facilities for long periods of time, probably feels like a cruel sentence. In fact, an article entitled, "What Is Old Age For?" in the fall 2005 issue of *Yes Magazine*, makes this allegation more succinctly than I. This was a genuine 'ah ha' moment confirming my concerns regarding Dad's situation.

The article actually compares nursing homes to prisons, and patients in nursing homes to inmates in prison. It may seem farfetched, but don't close your mind to the concept so quickly. If you can visualize the routine of one's day being the same daily, uninteresting and not stimulating, then possibly you can grasp how easy it is to slip into a state of depression. There is nothing new or stimulating to which to look forward. Both the elderly and prison inmates are detained in institutions and held captive in a physical, as well as a mental, state of confinement. The comparison is actually viable because of the routine and often permanent institutionalization of patients.

I am confident that the original intent of nursing homes or convalescent homes was not to imprison patients; unfortunately this seems to have become the consequence because many convalescent homes seem to have lost their benevolent objectives. They are often so bogged down by the quagmire of the healthcare industry. It appears as though rising medical costs have resulted in healthcare providers setting aside their initial priorities, which is the "well-being" of their patients.

Their rebuttal, I am sure, is that they focus on the overall health and safety of patients. Actually, this objective is probably what results in treating patients passively because it omits the emotional and psychological well-being of patients. It is for this very reason that many AD patients don't fare well in these conditions. These facilities have got to get back to hands-on-caregiving, which means "being in relationship" with the patients as individuals, and not just performing routine, robotic tasks for a group of patients.

The following case specimen is a communication from a former nursing home resident featured in the article:

"I have recently returned from 'rehabilitation care' in a nursing home. I have pretty severe cerebral palsy and had breast cancer surgery. The nursing home environment did more to slow the healing process than help. I got a terrifying glimpse into a future at such facilities. I would rather die than have to exist in such a place where residents are neglected, ignored,

patronized, infantilized, demeaned, where the environment is chaotic, noisy, cold, clinical, even psychotic."

This accounting of conditions in a rehabilitation facility is not just an unusual report of an isolated incident. I recall a similar article in the *AARP Magazine*, May/June 2010, entitled "The Secret Caregivers."

When a son visited his mother in a nursing home one day, he found her to be traumatized, unfed, and apparently untreated. When he asked the nurse why his mother hadn't been given her medication, she responded: "We can't give her any medication because we don't know who to bill it to." The son immediately called the medical director to have his mother released. The doctor initially refused, calling it an unsafe discharge. The doctor kept insisting that taking her out of the nursing home was against medical advice. Eventually the facility did relent and release the mother to the son.

The above account is exactly what we observed and experienced when our father was transferred to the convalescent facility for rehabilitation care, also referred to as a skilled nursing facility, in 2006 after surgery on his toe for gout. He became depressed, sullen, and there were episodes when he exhibited angry outbursts and tantrums, as described earlier. We observed him actually trying to fight for his independence. The staff kept saying that Dad couldn't walk. Dad kept insisting that he could walk, although he was seemingly confined to the bed when we visited. It was very confusing for us since we hadn't seen Dad walk since the surgery. However when Dad returned home after his release from the facility, he confided that he would walk to the bathroom at night when staff members were napping. You figure that one out!

The facility finally declared that Dad could walk again due to their rehabilitation services, and we thought he would be released and walk out of there. The administrators tried to convince us that he needed to remain in their care due to his mental and emotional state

of mind, and for his safety, of course. In other words, they wanted Dad to remain there for custodial or long-term care. We think it was for financial gain. They even implied that we could be liable for negligence if he was removed from the facility (without their consent for release) and subsequently injured. However, my brother and I were convinced that we did not want Dad to remain in that facility for custodial purposes or in any other facility for long-term care. We knew that we had to get him out of there for his mental and emotional well-being, and we did! After numerous meetings with the administrators of the skilled nursing facility, they reluctantly agreed to release Dad to us with responsibility for his care. It was also obvious on that day at the meeting when we were given Dad's release date that he could not return home to live alone. Part-time-caregivers were a thing of the past.

What happened to him? We didn't even have time to contemplate or comprehend what changed so significantly in a month and a half to prevent Dad from returning home with a part-time caregiver. But we knew we had five days to develop a 24-hour plan of care for him that now involved a live-in-caregiver.

Anxious yet determined to implement the best 24-hour care plan for Dad, my brother and I took into consideration the following: Dad's AD condition prior to the gout surgery; his tenure in the skilled nursing facility; his sincere desire to live in his own home; our ability to contribute to quality care in his home with the assistance of a live-in-caregiver; the ability to pay for the care in his home; and our ability to find a live-in-caregiver in five business days. Whew! This was a lot for novices like us.

At that time we were completely ignorant of the caregiver business, an industry encompassing nursing homes, convalescent homes, assisted living facilities, adult day care facilities, residential group homes, in-home-care agencies, and registries. I even revisited the nice assisted living facility, but this time I only toured the AD quarters. It was very disheartening to see people sitting around in large groups: asleep in their chairs, slumped over, with glazed sad

eyes, drooling, many mumbling to themselves, several in hospital gowns, some yelling, or begging and crying, and seemingly all were ignored.

It just felt cruel to place Dad in living quarters where people seemed to merely exist more than live, and which was, predictably, very expensive. Our cursory investigation revealed that agency and registry fees for live-in caregivers were prohibitive for our budget, a whopping \$3,000-\$3,200 a month for salaries –the equivalent to \$36,000-\$38,000 a year in 2006. Ouch!

This preliminary information was shocking. We kept contemplating our budget and how much could we pay a caregiver, to be competitive with the market and in line with affordability and our personal ethics about worth, fair wages, and compensation.

Desperate, and this definitely is the operative word, to honor our dad's wishes to remain in his home, my brother and I set out to find live-in-caregivers on our own. This is often referred to as a *direct pay arrangement* with independent caregivers who are seeking work on their own, apart from and independent of an agency or registry. Our objective was to ask friends and relatives for referrals to people who provide caregiver services, and to seek referrals from adult day care and other senior care programs.

Three days before our dad's anticipated release date from the skilled nursing facility, I received a good lead from an administrator at an adult day care center who recommended her mother. She described her mother as having a pleasant personality, prior history with in-home-care patients, very reliable, and equally important, she thought her mother would accept the fee we could afford. I met and interviewed the mother, took her to Dad's home, and explained my perceived routine for Dad's care in his home. She seemed amicable, accepting and willing to do what we expected of her at the salary we offered. The next day I took her to meet Dad at the facility. She even took the initiative to recommend her cousin, who was also available to be *her* weekend relief person. Two days later, Dad was released

from the facility. My brother and I, and our first live-in-caregivers all arrived at the facility to accompany our dad back to his own home.

When Dad arrived home, we observed an immediate calmness and sense that he felt he belonged there. This disease is so unpredictable. On one hand, when Dad sat down in the den, he looked around the room very contemplatively. Yet when he walked into his bedroom he smiled, instantly noticing a new rather colorful bedspread. He immediately commented on how nice it looked and how comfortable the room appeared. In that moment, we were filled with relief and exhaled. We had made the right decision to bring Dad home. Incidentally, I moved in with Dad to oversee the transition of having total strangers living in his home.

In November 2006, when Dad was 87, my brother and I requested another evaluation from dad's HMO because of our concern about the apparent progression of his AD. His score from this MMSE was 19/30. He had lost seven points since his first score in 2004. I'll always wonder if the general anesthesia in surgery and Dad's stay in the rehabilitation unit contributed to this rapid deterioration.

CHAPTER 4

LESSONS



The first direct pay live-in-caregivers we hired in 2006, lasted one year. We stressed to the two caregivers that they were needed to secure Dad's health and safety, and for social interaction. At the time, he had no serious medical problems. Blood pressure and cholesterol were stabilized with medications. A caterer prepared dinner meals since neither caregiver cooked very much. They were responsible for preparing breakfast, usually oatmeal, and lunch. They were expected to keep the house clean, with emphasis on bathrooms, bedrooms, kitchen, and the den. They did Dad's laundry and their own. A car was required because Dad enjoys going for a ride during the day, especially since he was accustomed to getting in the car and going at his leisure.

To the surprise of many, we allowed the caregivers to do their own personal errands on our dime, which was considered very unorthodox. In fact, one home health agency warned us that this incentive could be a slippery slope. We considered this a bonus, along with room and board, meals, and a full night's sleep during their shift.

Looking back in hindsight, we should have also required the caregivers to present a recent medical checkup as well. We did not. It became apparent that both of these caregivers had health issues that had not been disclosed during the initial interview. One withheld serious health information about hepatitis and a kidney ailment.

The other was depressed and had other serious undisclosed health issues that became apparent later. We had not required a physical to be taken because it entails a financial expenditure on the part of the in-home-caregiver. Naively, we trusted that they would have disclosed this information in the interview.

The experience with these two applicants provided the first among many lessons we've learned on hiring caregivers. First, it became very evident that my brother and I were really on our own in this caregiver journey. For example, home health agencies do health clearances and criminal record checks, but there is no way a caregiver with hepatitis would be registered with an agency or registry with a health risk such as this. We also had to be honest with ourselves and acknowledge our desperation in hiring the cousin, the relief caregiver. In retrospect, my first observation was of her depressed demeanor, although she tried to be pleasant. She was very overweight and didn't look healthy. The lesson learned here is to *follow your first mind and to trust your intuition*. I also recommend that you request a TB clearance and copies of the results of a recent medical examination. You cannot afford to be lax in your interview because it can be detrimental to the health and safety of your loved one and you.

Further, "naivety" can be a liability. I trusted the recommendation of an administrator from an adult day care facility, thinking she was a person of integrity. Later it was very apparent that she knew of her mother's health issues. It was mind blowing to realize what people will do at the expense of your loved one's well-being. At the end of the day, it was our responsibility. We should have taken steps to be more aware of the people we were hiring to care for our father.

Our second direct pay live-in-caregiver lasted approximately two years, from 2007 to summer, 2009. She was ultimately terminated because of health issues as well, which became apparent through observations of extreme mood swings, an alleged thyroid ailment, and a credible allegation of drug use. Throughout her tenure, several things went missing, such as jewelry and money. But Dad always looked clean and the house was kept neat and sanitary. People were

always complimenting me and my brother on how attentive this caregiver appeared to be with Dad.

In May 2008, when Dad was 88 years old, we requested another MMSE. This time his score dropped to 14/30, which was a loss of 12 points since January 2004. The doctor noted in his medical records that his decline was consistent with his diagnosis. His assessment summary was that Dad was in the *moderate-severe stage of dementia of the Alzheimer's type*. The doctor recommended adding another drug called Namenda along with the Aricept he was currently taking because it could help him maintain functioning for an additional period of time.

This second caregiver ended up having undisclosed health issues that I assumed caused severe emotional and behavioral problems. Out of desperation again, we had hired her immediately after terminating the first two caregivers because of their physical and emotional issues. Again, all this because we were unprepared to properly screen potential caregivers for Dad due to the same circumstance of desperation to have a long-term caregiver for him.

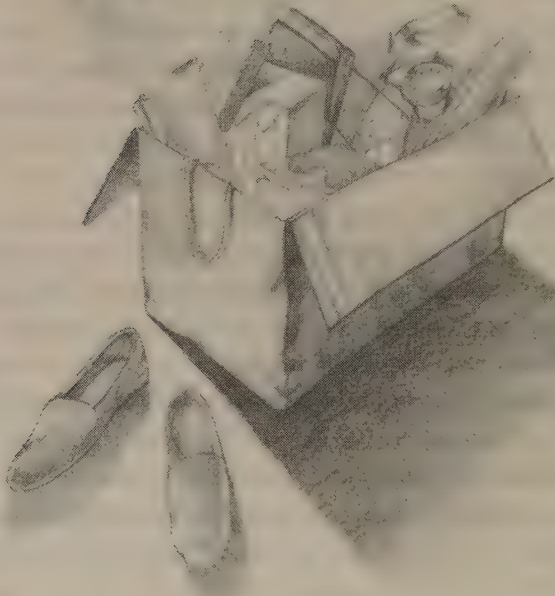
In our defense, we just weren't familiar with people who lacked integrity and lied about their background. I realize now that we were in denial, which accounts for the reason why my brother and I didn't make the connection with the second caregiver's defiance, temper tantrums, and severe weight loss to drug abuse. We were concerned about the questionable behavior, but the caregiver constantly apologized and reported that it would be resolved by means of thyroid treatments scheduled in the near future. Obviously, we were even more in denial about her behavior because of our desperation to make it work with her. Her behavior problems surfaced at the end of her second year working with us.

Originally we had rationalized that we didn't need to request medical clearances because the caregiver appeared healthy. In addition, she had previously been registered with a healthcare agency that required medical clearances. I was able to verify her employment with the agency, and her personal references checked out. We

had no reason to think that she was lying about a thyroid condition. However, I discovered later that one reference had been her best friend. Think about it, you don't know who you're talking to over the phone when you call a stranger. You're just calling a name(s) and phone number(s) given to you by the caregiver. I suggest that you call the references during the initial interview, which may throw them off in coordinating their "stories."

After the second caregiver, it became evident that you should also take pictures of anything valuable in the home or remove those items in order to avoid them being misplaced, broken or stolen. Even further, you may want to consider installing monitoring devices in your home.

It was another relief caregiver that we had hired for weekends who informed us that the regular live-in-caregiver was using drugs. It's very possible that she could have been the one to have taken what we thought were missing items, such as our dad's jewelry. Since AD clients are notorious for hiding things and alleging that people are stealing from them, and frankly we assumed this was the case. The caregiver had convinced us that Dad had probably hidden them somewhere in his home. Of course she would want us to believe that if she had taken them. And the truth is, we wanted to believe it as well.



My brother and I have since then taken many of Dad's personal possessions from him for his own health and safety. His wedding ring was removed because his finger would swell and it appeared as though the ring was cutting off the circulation in that finger. We tried to explain, to no avail, that he was bruising his finger fidgeting with the ring. He was twisting and pulling on his very expensive watchband continuously and unnecessarily winding the knot on his self-winding watch to the point of requiring numerous repairs. In addition, since all of his jewelry was very expensive, my brother and I decided to remove them before an unscrupulous caregiver did. An expensive gold chain had already come up missing.

We had already taken his two cars and the keys from him, upon the doctor's recommendation; since it was determined he should no longer drive. This decision really disturbed Dad, who became visibly upset. He began inquiring as to how he would get around and what he would do without a car. We took his house keys from him for his safety. We took his wallet from him because the money we placed in it kept coming up missing with no explanation. Dad wasn't buying anything. Or should I say, he shouldn't have been buying anything. Dad began to verbalize that things were "missing." Further, he said that things were being changed and moved, and in fact, they were. He was cognizant of that. Our efforts to tell him that we had taken his personal items for fear of them getting lost were futile because he wouldn't or couldn't remember our explanation. I can only imagine how it must feel for things to be taken from you and you don't know why. Unfortunately, regardless of our intent to take things from Dad in order to protect him, it probably resulted in him feeling violated and that things had been stolen from him and obviously we were considered the thieves.

Primary caregivers cannot take these types of allegations personally because AD is the real thief. Gone, are the AD patient's memory of why things have been removed, as well as the reason why he cannot be held accountable for himself and or his actions. At one time we even tried to replace the expensive items that were removed with less expensive ones, but that made us feel worse to see Dad wearing a cheap watch purchased by us, until he tried to destroy that, too. Finally, we decided that whenever things were removed or destroyed, they simply would not be replaced.

In 2009, there was a series of caregivers, two of whom came through a home care agency recommended by a friend. This agency agreed to work with us within our budget. But both of these individuals turned out to lack skills and professionalism. For example, on one occasion Dad fell in the early morning while getting out of bed, we assume, to go to the bathroom. This caregiver helped him up because he could not get up on his own and put him back in bed. She didn't call to inform either my brother or me about Dad's fall; nor did she

call 911, when he couldn't get up. This shows a lack of qualified experience because she did not know whether he had seriously injured himself or fractured any bones. Falls of the elderly should always be reported so that they can be observed, diagnosed, and treated by a doctor because their bodies are delicate and fragile. They can incur internal damage not visible to the naked eye. When my brother came over to the house to visit Dad that evening, the caregiver just nonchalantly mentioned the incident to him. She had also omitted logging the incident in her daily report as required. The individual who replaced her came from the same in-home-care agency. She was constantly complaining about her unhappiness with the wages she agreed to with the agency. These were issues that needed to be handled with the agency and not us since the caregiving fees were sent directly to the agency. She also seemed moody and not attentive to Dad's needs. She terminated her own services a short time after being hired and without notice, leaving us without a replacement.

So what is the moral of this lesson? Some may say, "You get what you pay for." The healthcare agency had given us a discounted rate for the last two caregivers whom I simply referred to as individuals hired in 2009. Unbeknownst to us, we seemed to have paid for less professionalism, less skills and training, and less compassion. Who knew?

February 2010, it was recommended that Dad undergo a serious, rather high risk surgery involving putting a rod in his head-neck area in order to stabilize his head. Degenerative arthritis on the right side of his neck had caused his head to be so unstable that a fall or sudden jerk could possibly result in paralysis. The actual medical terminology was that Dad had a 'C1' dislocation requiring an occipital-cervical fusion. We got a second opinion, which confirmed the first diagnosis. Our major concerns about the surgery were Dad's age and the impact the surgery could have on the progression of AD, and quality of life. However, Dad was so physically strong that we elected to do the surgery because it could influence his quality of life. We decided to take our chances, or should I say take *his* chances, on whether Dad would return to *baseline* after the surgery. "Baseline" means where Dad was mentally and cognitively

before the surgery. In other words, we wanted to know whether this surgery, which involved general anesthesia, would have a negative effect on AD. The doctors, of course, could give no guarantee! You know how guarded doctors can be. This piqued my curiosity again – the relationship between the surgery, the general anesthesia, and the effect on the brain as it pertains to AD.

Dad came through the surgery with flying colors. The doctors were amazed about his physical strength, rapid recovery, and overall health. They commented daily on the muscles in his legs, arms, stomach, and overall, how strong he was. I realized that he was living proof that if you don't abuse your body, and if you exercise and eat properly, a disease as serious as AD may not negatively impact the body of a healthy person as severely as an unhealthy person.

On the other hand, however, the surgery seemed to have exacerbated the AD by stealing more of his memory. After being released from the skilled nursing facility for rehabilitation after the first surgery (for the toe gout), he returned to his home happy to be back. This time when he returned, he didn't recognize his home, and to this day often doesn't realize that he is living in his own home. He is, however, very relaxed and comfortable in his home, and knows his way around the house some of the time. He rarely says my name or my brother's name, and periodically refers to his in-home-caregivers by our mother's name. We observed that he has increased episodes of confusion, anxiety, and insomnia. Our dad clearly did not return back to baseline after this surgery. He had a "new normal."

During Dad's last hospital and convalescent stay in 2010, we utilized the services of two Certified Nursing Aides (CNAs) for two 12-hour shifts for approximately three weeks, the duration of Dad's hospitalization. Unfortunately, the two caregivers providing in-home-care prior to his hospitalization had schedules that could not accommodate the 12-hour shifts. So we understood when both of them informed us that they decided to move on because they needed to work. Nevertheless, we had become very impressed with the caregiving skills of one particular caregiver, a referral who reported for duty during Dad's hospital

stay. Her personality, knowledge, training, and experience stood out over many of the past caregivers. She seemed to be “present” with our dad, and was very nurturing and engaging with him. Her prior experience in working with AD patients was quite evident by her interaction with him. He, in turn, responded to her very well.

Daily outings were always crucial to Dad’s emotional health. Yet one real issue was this particular caregiver didn’t have a car at the time. This posed a real dilemma in our decision to hire or not hire her. She said that she planned to buy a car in a couple of months. And, once more, we were desperate because Dad was being released and we didn’t have anyone else. I had to wonder, how did we end up here again? We rolled the dice yet again, and offered her employment as an independent contractor for 24-hour live-in services, five days a week. It would be a direct pay arrangement.

She accepted our offer as an independent contractor. We were elated. Her skill-set and the timing of her hiring was a perfect complement to the decline Dad was experiencing after his release from the skilled nursing facility. One down and one to go!

The daunting task of finding a weekend caregiver, the relief person, was still ahead of us. Often, that’s even more difficult than finding a weekday person because people like to be off on weekends to rest or simply to participate in social activities, or to attend their place of worship. Also, most caregivers we interviewed were seeking full-time work opportunities. However, we learned that many will accept the weekend position even while continuing to look for their desired full-time job. So we needed to communicate clearly that we were looking for services on a long-term basis, as well as determining the caregivers’ real intentions.

Subsequently, we brought Dad home from the skilled nursing facility with the caregiver who had connected with him during his stay in the hospital and the skilled nursing facility. During this same period, we had hired numerous relief caregivers, which I think was very unfortunate and very unsettling for Dad. It was equally, if not

more, stressful for us. Since as we observed each caregiver individually after being hired, we realized they just didn't have what we were looking for. During the interviews, many of the caregivers would casually tell us what they thought we wanted to hear, "I love to cook. I love to clean. I love old people." One consistent flaw was they all seemed to be content with encouraging Dad to nap all day. This lack of stimulation leads to boredom and behavior problems during the day and insomnia and sleeplessness for all at night.

I observed that many of the individuals who claimed to be caregivers who enjoyed working with older people, were actually uncomfortable in Dad's presence. In other words, his AD symptoms made them insecure and they were uncertain how to communicate with him or handle his increasing periods of confusion and social inappropriateness. Consequently, they avoided interaction by putting on the television and letting him sit all day and nap from boredom. They cleaned drawers and threw away items without seeking our permission. We literally found drawers that had been filled with various items now completely empty. We really didn't have a clue what was in them. As a result, we didn't know what was thrown away or taken. But that is not the point. Things should not have been removed without permission. In addition, some of Dad's food, clothes, sheets, and toiletries could not be unaccounted for. We don't know whether these missing items were intentionally raided, or just part and parcel of the unauthorized cleaning sessions. Another unprofessional practice that I recall is that some individuals gave Dad medications like sleeping pills and sedatives which they found in the cabinets, without our permission. This contributed to his lethargy during the day even as the caregivers complained, "He sleeps so much."

It was also during this time that our dad's social security card, Medicare card, and California ID all went missing. Disappeared! Upon inquiry, no one knew what happened to the items. We could not identify the exact period they came up missing because they were placed in a drawer with other personal identification not required by him daily. This was such a contentious period, who knows what happened to Dad's personal items, household items, and personal

identifications. This really unnerved me because not only was AD stealing from Dad, but also the caregivers appeared to be literally robbing him of so many material things.

Consequently, I began to be extremely suspicious about the training, or should I say the lack of training, reported by the caregivers, as well as the lack of integrity of many of them. All of the caregivers had reported experience working with AD patients, which was verified when we followed up by calling their references, whether from agencies or otherwise. My brother and I had also begun to question ourselves about our interviewing and screening techniques as well as our people instincts. Why didn't we see through these people one after the other? We had naively relied on the fact that most of the caregivers we hired, who had reported prior caregiver experience with AD patients, were registered with in-home-care agencies. Many were registered with an in-home-support service union in the State of California. Therefore, they had been live-scanned and had health clearances. And, of course, the references they provided were always good. Dad had always reported to us, when asked, that everything was fine. We knew he wasn't the best reporter. However, I was constantly assessing his mood, which was basically good. There were no unusual visible bruises or emotional affects.

So what was the missing link(s) in our father's care that could be more empowering to him: provide a more stimulating environment; and a better quality of life; and finding a better caliber of caregivers?

We had already established that no type of out-of-home care seemed appropriate for Dad at that time. He definitely wasn't convalescent or nursing home material since he was physically strong and ambulatory. On the other hand, Dad was not independent enough to live in an assisted living facility, which was definitely more home-like, and also provided social outlets. They provide a room, meals, activities, supervision, and assistance with tasks such as bathing, dressing, and eating, although they do not provide nursing or medical care, if or when needed. Since adult foster homes and residential group homes were in fact homes, shouldn't we be able to find a way

to keep Dad in his own home, I mused. Why move him to another residential home now when he had a home? Why take his home from him and all that is familiar? Why can't we find stable, compassionate, and reliable caregivers? I had then gone full circle in my thinking and began to reconsider the feasibility of out-of-home care, right now.

It was during this contentious period that I decided to look for sources other than his HMO to monitor Dad and the progression AD. In March 2011, my brother and I took him to be evaluated at a large prominent school of medicine in Los Angeles, California for consideration for participating in a clinical trial. They administered the MMSE, and reported Dad's score to be 6/30. Further, he was assessed with *severe cognitive impairment*, and did not meet the criterion for any of their current clinical or research studies. I was in shock! He was so physically healthy and strong, but the doctor overseeing the evaluation process told us that physical health had nothing to do with AD – it was all about the loss of memory and cognitive decline. I liked this doctor's bedside manner. She was firm yet compassionate, and I vowed to stay in touch with her.

Soon after, I came to terms with the fact that genuine love may be the foundation for our efforts to provide quality care for our father. Still, an oppressive love that enables and robs the independence of an AD patient is detrimental, whether unintentional or not. Being overly protective is not the answer. A more nurturing love encourages the patient to be independent for as long as possible. We were so busy trying to keep our dad safe that we forgot that real living is about doing and not just about existing. Dad really needed to feel like he was living, not merely existing. He needed to be a contributing part of the household. When Dad would ask if he could help with little chores like bringing in groceries, we would say, "No, you just sit there, we'll do it!" as though he were helpless. In retrospect, although dad couldn't carry groceries and navigate the walker, we could have hung a small bag of groceries on his walker. This way he would have been participating in helping with the task. But, thanks to us, he was just relegated to watching us do the work.

Dad was constantly asking what he could do to help. We always said, "Nothing, you just sit there."

Whenever I visited Dad and observed him just sitting around looking very bored, the constant refrain from caregivers was, "He's old and needs to rest." Dad may have been 90 at the time, but he looked like he wanted to do something more than sit and sleep the rest of his life away. He had always been very active, not one to just sit and let time pass him by. I had developed a daily schedule as a guide for caregivers in the past. But, I began to realize that it was inadequate because it was just a daily routine. Dad needed more support; therefore the caregivers needed more direction. We really needed to look closely at his activities and interests and assess if and how we could incorporate them into his daily living activities as an AD patient. I decided a personal care plan for Dad, not simply a daily routine schedule, was a missing key component.

Another 'ah ha' moment occurred when I assessed that many of the previous caregivers were doing their job of performing routine tasks of providing personal care by assisting with bathing, dressing, and toileting activities, and household tasks of cooking, cleaning, laundry, some shopping, and dispensing his medications authorized by us. Our dad was taken care of physically, but mentally and emotionally, we were stealing what remained of his mind, because we were robbing him of his independence and his desire to participate in life. He really needed a more hands-on caregiver who was in relationship with him. One who would talk and laugh with him and participate in activities with him.

Just as an example, we already required getting Dad out of the house because he likes to go out and about. He appears to simply enjoy the ride in a car! It's the one thing that he still consciously misses because he used to get in his car and go. We provided direction to caregivers to interact with him and get him to do things he used to love doing like playing cards, board games, watching and talking about basketball. We also ask that they engage him in activities that he can do, like helping with chores around the house such

as folding the laundry and opening the shutter windows in the morning. Such activities do matter, whether large or small, because they help to keep him in the moment as an active participant in life.

Eventually, the once familiar environment of the AD patient becomes foreign. As inconceivable as it may be, our father no longer recognizes the home that he has lived in for almost a half century. Although his home environment has been adjusted to function as simply as possible for safety reasons; ultimately, our goal is to keep it as comfortable for him as long as possible and as close to the way it was before the onset of AD. There have been no abrupt changes in his home like conspicuously moving the furniture around or dramatic paint color changes. I have learned that too much stimuli affects the perception of an AD patient. A trained caregiver should be particularly cognizant of lighting as well as other things that affect the AD patient. For example, daylight is considered to be the most comfortable kind of light for them, so open the blinds and drapes. In winter months or on dark dreary days, turn on the lights to try to simulate daytime.

Any reasonable activity that an AD patient is able to perform *let them do it!* I begged caregivers to utilize Dad's compulsive behavior of folding and refolding things by allowing him to assist with folding the clothes. I have observed him looking very content as he meticulously does this activity. I think he feels a sense of accomplishment and that he is contributing to the household instead of just sitting and watching activity around him and being left out. These small accomplishments confirm and reaffirm that we're making the right choices for Dad.

I gradually realized that my brother and I needed to adjust our attitude; we needed to be on a mission to learn more about AD and focus more on the humanistic side rather than the clinical side. I needed to apply my social worker skills and stop being a doting daughter. I needed to design and implement a more personalized plan of care. Without a doubt, this personal care plan was going to become much more patient-oriented than simply following a daily schedule. Definitely, we needed to become more skillful in interviewing and

screening caregivers, and training them in our personal care plan for Dad. It had become apparent that we weren't asking the right questions in our interviewing process. In fact, as Claudia Ellan-Ota, Director of the Caregiver Resource Center of Orange County, reported in Rosemary McClure's monthly column in the July 9, 2011 issue of the *Los Angeles Times*, "People try to fly by the seat of their pants when they hire help for their parents." A primary caregiver named Ann confessed, "Unfortunately, many well-meaning and caring adult children are just as lackadaisical as I was when hiring help for their parents". Wow! That statement hit me like a splash of cold water in the face. My brother and I had become careless in our desperation to hire caregivers, which could have been detrimental to Dad. That thought felt like a low blow to the pit of my stomach. It was also during this analytical and introspective period that I realized there is a distinct difference between caring for a patient with a physical disability and one with a brain disease. Many caregivers think they have worked with AD patients or think they can work with them because they have worked with patients suffering from other illnesses with symptoms similar to AD and other dementias. Actually, in fact, they have not worked with an AD patient and are not prepared, and many are not even motivated to learn.

When interviewing a prospective caregiver, we had to learn how to ask meaningful questions, which confirmed their alleged experience or lack of experience as well as knowledge of AD. (I will discuss the specific types of meaningful questions that I have developed and compiled into a topic called "Suggested Interview Questions for AD Patients" later.)

Armed with over 30 years of social work skills and training, a new perspective and renewed sense of purpose, I set out on a mission to visit, assess, and read numerous brochures about convalescent homes and residential care homes. This resulted in my decision to implement some aspects of their concepts emphasizing consistency and routine used by these facilities. Most convalescent and nursing homes have treatment plans that manage the care of patients, which could involve physical therapy, medication, and drug therapy,

just to name a few. However, a convalescent home by sheer definition is technically not the best place for most AD patients. *Webster's Dictionary* defines "convalesce" as "to recover, rehabilitate, to recuperate, and to mend".

Several established AD clinicians will tell you that there is no actual treatment for this disease except good quality care. You don't get better if you have AD. You have good days, but you don't get better, according to most documentation regarding AD. If you were diagnosed with AD and you got better, you may have been misdiagnosed. In fact, I know of a situation where a lady was diagnosed with AD, began taking the medication Aricept, and started to improve. The doctors basically said, "Oh we made a mistake, you have Vascular Dementia, not Alzheimer's Disease." That is why it is crucial for lay people like us to try to gain an understanding of the basis for their patient's diagnosis. There are treatment options for Vascular Dementia. You should know, there are medications that may slow down the progressive symptoms of AD, but currently there is no cure for this disease at the time of this writing.

Patient care professionals should establish that AD patients need attention, interaction, and caregivers who are in relationship with them. Nursing homes are designed essentially for comfort care. In the terminal stage of AD, comfort care is the main goal. But until that stage, many seem to benefit more from mental stimulation, and nursing homes are not necessarily geared to provide a stimulating environment. Many AD patients need to feel active, involved, and want to contribute to something meaningful during their day. These AD patients need an environment where they can be encouraged and motivated, especially in the early and middle stages of the disease. They need individual attention and emphasis needs to be put on their individual strengths rather than what they can't do.

On the occasions that I've toured convalescent homes, AD centers, and special care units, it reminded me of the term "cattle call" used in the movie industry, when casting directors are looking to cast extras for a group scene. The scene requires a lot of people

who basically all do the same thing like sitting in a big restaurant dining, walking on the street, or as fans at a football or basketball game. Similarly, many care facilities are not designed to cater to the individual. If you walk in, you witness the patients in a group scene *in character* as patients sitting in chairs and wheelchairs doing little or nothing. Therefore, we elected to keep Dad in his home and apply a strength-based plan of care to our personal care plan designed just for our dad. And you, too, can design a personal care plan tailored for your patient.

In my vocation as a social worker, I've always advocated for a strength-based plan of care for my clients. For approximately 25 years, I worked for the Department of Children and Family Services in Los Angeles, California. Advocating for the protection of children and their basic rights to adequate food, clothing, shelter, health, safety, and appropriate resources and services were my primary responsibilities which I did focusing on their strengths. A strength-based plan of care focuses on identifying and incorporating the patient's concerns and the family's strengths, rather than deficits, in determining a viable plan. (The core belief of this concept is that all patients and families have strengths) Patients and their families deserve to be treated with respect and dignity; patients and families can make well-informed decisions about keeping their loved ones safe when supported; and when possible, families should involve the patient in the decision-making process about their future. In addition, the strength-based plan of care allows the patient and family to work within their cultural and family context. When an AD family member is placed in a convalescent home, or even a residential group home, they often lose their autonomy and their cultural and family context that essentially reminds them of who they are, and supports them.

A personal care plan, from the perspective of strength-based for an AD patient should – in my view – reflect a patient's life course, because it is important to know from where the patient has come. In other words, what is their personal history? Insight into the major influences and highlights in a patient's life helps you to construct a

personal care plan that is as close as possible to the activities in their life before the onset of the symptoms of AD.

Although we don't hear as much about elder abuse as we do about child abuse, it does occur at alarming rates. I am pursuing the same sort of advocacy for the elders as my brother and I struggle diligently to seek the best care for our father in his home. I think elder abuse is going to become an increasing phenomenon as the numbers escalate, if there is not heightened awareness on how to manage AD. Similar to most children under court jurisdiction in the Department of Children and Family Services who would rather live with their parents or relatives, most adults with AD would rather live in their own home or with their adult children, or relatives and other loved ones. With AD, the relationship of adult child and adult parent often becomes reversed, and many adult children become guardians to their parents, who exhibit child-like behaviors and have safety and health issues as a result of this degenerative disease. However, these behaviors should not mitigate the dignity and respect due to our parents, who have a lifetime of knowledge, experiences, and overall wisdom.

I can recall decades ago, when children were considered *at risk* when they were left home alone. Children who arrived home after school to an empty house because parents were still at their jobs were referred to as *latchkey kids*, and that was often considered a form of child abuse. I fear that this phenomenon is going to rear its ugly head again – this time with AD adult patients who are *locked-in* the home, allegedly for their safety, when primary caregivers go to work or leave them in the home alone for long periods. In my opinion, this could be considered elder abuse because of the health and safety issues due to impaired judgment and other cognitive challenges of AD. If you don't secure the home, many AD patients who are wanderers leave the house, get lost, and can't remember how to get back home. Some can't remember addresses and or phone numbers. They can easily fall, also set fires, drown – anything can happen because their cognitive thinking is impaired and they are not responsible for their actions. This is going to become a huge challenge trying to keep AD patients safe when primary caregivers

have to work. This is the plight of many Baby Boomers now and it will increase substantially in the near future. All of these issues and concerns should be addressed in the plan of care for the patient.

The overall goal in creating the personal care plan is to make every effort to keep the AD patient's daily routine and activities as constant as they had been all their life, and definitely as regular as they were before the onset of the AD symptoms. Before creating your personal care plan, I believe it is important to be familiar with the stages of AD before committing to this huge responsibility in personal care. The stages categorize the changes that *may* occur with a patient as the disease progresses. Don't forget that *may* is the operative word.

CHAPTER 5

PROGRESSION, THE STAGES OF AD



When our father was initially diagnosed in June 2004, he was allegedly in the mild-moderate classification. His numbered stage was a “20” on a scale from zero to 30 derived from a range of questions and tasks that tested his functional, cognitive, and mental abilities. Unfortunately, many experts in the field have developed their own set of AD stages and numbering that can vary from three stages to seven stages.

Many healthcare professionals no longer use the numbered stages. Instead, AD patients are classified according to the level of their cognitive and functional impairment, i.e. mild, moderate, severe, and profound. Cognitive skills relate to the patient’s ability to think, make and carry out reasonable plans, make judgments, awareness, and ability to learn and retain new information. Functional skills, on the other hand, relate to a patient’s ability to manage their own care and carry out their daily activities, including personal hygiene, feeding and grooming one’s self. The following is a brief description of the stages and some general symptoms:

EARLY STAGE

This is the beginning manifestation of what many clinicians refer to as “a long slow downhill course.” I have also heard it referred to

as “the long good-bye.” Symptoms in this stage are so subtle that a great number of patients and their families and friends don’t recognize them as cause for concern and ignore them.

The primary symptom in this stage is memory loss, which is periodic and inconsistent, and increases over time. The patient continues to perform most of their daily activities, and compensate for many others. Unfortunately, those activities that become challenging are often associated with age, stress and fatigue, which often may be a rationalization for both the AD victim and the family observing the behavior. Some examples are losing items, the inability to recall words or names, oversights in writing checks and paying bills. Depression is common during this stage. I have a poignant example of a man who started noticing a decline in his memory that was significant enough to prompt the following letter (the name has been changed to protect the privacy of the individual):

Dear Sir,

I recently read about your product, “Memory Prescription” and was very interested.

I am a 71-year-old retired CPA, and alumnus of UCLA. I have taken a course on memory improvement, but it has not improved my ability very much. I once had a semi-photographic memory, but the skill has rescinded. Is there something in your development that might help? I would appreciate any help you could offer me.

Peter Hill

Los Angeles, CA

Peter’s ex-wife shared this letter with me to assist in my advocacy for AD patients. She found the letter while cleaning out her garage to prepare for a yard sale. The letter was not dated and was written to a doctor at the *Center of Aging Department* of a prestigious college in California. I share the letter in order for you to see how important it is to recognize and not ignore memory loss – that cunning, crafty, telltale sign of AD.

What resonated with me about Peter's letter was his acknowledgement that something was wrong or significantly different about his memory. Peter was not in denial and he took the personal responsibility to seek help. Unfortunately, we don't know whether Peter got help at the time. Today, reportedly, he is wasting away in a nursing home. His ex-wife is currently advocating on his behalf. She described him as looking like a zombie. He appears over-medicated and simply hopeless. He's wheelchair bound and eats with his hands. She contacted his conservator and suggested that his medication be reduced. The moral of this story is AD patients, especially single ones, need trustworthy individuals to be an advocate on their behalf since they cannot do so for themselves. She has reported that he looks cleaner and better, and she feels more hopeful about his care.

TESTING

Wouldn't you rather be ahead of the ball than chasing it? Do not under estimate the benefit of recognizing the warning signs of AD and acting quickly. Get a professional evaluation and diagnosis! Vascular Dementia, for example, is the second most common type of dementia and is more prevalent in one ethnicity than others. Can you guess which one? Strokes are the cause of this dementia and can destroy the brain tissue to a significant extent. Some of the symptoms look similar to AD, resulting in a misdiagnosis if not properly diagnosed. ✕

Another curve to add to the mysteriousness of correctly diagnosing AD: Although a person may have noticeable difficulty with memory or other thinking skills, a doctor may determine the person does not meet the criteria for being diagnosed with AD. Some doctors refer to the term Mild Cognitive Impairment (MCI) to describe this situation. It is characterized by memory impairment without impairment of other cognitive or functional abilities to the extent beyond that expected for the patient's age or educational background. Reportedly, research has shown that individuals with MCI have an increased risk of progressing to AD. A diagnosis of MCI doesn't always mean that the person will develop AD. Knowing

this, however, can be critical in being prepared for the possibility of AD. I will discuss MCI in greater detail in another chapter.

Regarding Dad, several clinicians commented that Dad's score of 20/30 was low and implied that he was more advanced, and probably not in the Early Stage of the disease when he was initially diagnosed. This means that he had noticeable symptoms of AD that we had missed or inadvertently dismissed as grief. For example, in June 2004, Dad was exhibiting the following classic AD warning signs:

- Memory loss
- Loss of initiative
- Change in mood
- Difficulty performing familiar tasks
- Disorientation to time and place
- Misplacing things

These warning signs represent a little over half of the ten warning signs reported by the American Alzheimer's Association. Sadly, we just weren't aware of any warning signs of AD in 2001, except memory loss. For this reason, I am providing critical information used in clinically diagnosing AD patients. Hopefully, this information will assist you in determining whether to obtain a professional assessment for yourself or your loved one. Time is crucial! When Dad took the MMSE Test in 2004, which determined his diagnosis, listed below are some of the areas in which he was evaluated:

1. Orientation to time
2. Orientation to place
3. Attention
4. Recall
5. Naming objects
6. Repetition
7. Comprehension
8. Reading
9. Writing

10. Drawing
11. Depression
12. Memory
13. Judgment and problem solving
14. Community affairs (i.e., U.S. president, mayor, etc.)
15. Home and hobbies
16. Personal care
17. Language

The clinicians allowed me to stay in the room while he was being evaluated. I tried to pretend I was reading a magazine because I did not want Dad to see or feel my reactions to his participation in the evaluation. I was actually shocked that Dad didn't know who the current President of the United States was at that time. He read the paper daily, or so we thought. So I asked myself the question, was he really reading the paper or had he been pretending just as I was doing right then? Or still, was he reading, but forgot what he read once he finished? I was equally surprised that Dad couldn't draw the hands of a clock to show two o'clock when instructed. I have no explanation or theory on why he did not know who the president was, but I knew that he could tell time because often I asked him what time it was, and he told me the correct time. Could there have been a slight bias in determining whether a person could draw the time as compared to telling the time? Perhaps the idea of drawing is daunting to some. Or there may be a failure to recognize that people respond to questions differently? Although the diagnostic devices used that day appeared subjective and even culturally biased, I did personally observe Dad's diminished ability in the areas of judgment and problem solving, comprehension, orientation to time and space, and attention. How did all these changes occur under our watchful eyes, I pondered?

It wasn't until I requested Dad's medical records and actually scrutinized the categories in the MMSE that I realized how his initial symptoms had evaded us. For example, the Orientation category of the MMSE basically assessed Dad's awareness of himself and what's around him. The clinician asked him what day, month, year,

and season it was. He asked if Dad knew where he was currently. In other words, what HMO he was in, the floor he was on and the address, city, county and state. Dad did not know.

In the category of 'Recall,' which tested his memory, the clinician would say, "ball, flag and tree" clearly and slowly, wait a minute or two and then ask Dad to repeat the words, "ball, flag, and tree," testing the ability to recall information. In the category of 'Attention and Calculation,' the clinician asked Dad to begin counting from 100 backwards by 7 – i.e., 93-86-79-72-65. He also asked Dad to spell the word *world* backwards. Then the clinician asked Dad to recall the three previous words, "ball, flag and tree." Again, he was testing memory and recall.

In the category of 'Language,' the clinician showed Dad a wristwatch and a pencil and asked him to name it. In the category of 'Repetition,' the clinician asked Dad to repeat "no ifs, ands, or buts." In the category of 'Writing,' Dad had to write a sentence that contained a subject and verb and made sense. In the category of 'Copying or Drawing,' the clinician told Dad to copy two intersecting pentagons. All ten angles had to be present and two or more had to intersect to be considered correct. Lastly, Dad was asked questions which determined whether he was depressed or not.

I've shared the contents of this MMSE to increase your awareness about the test process and what clinicians are looking for. It never entered our minds to test Dad's ability to recall information. We knew his memory was getting worse, but we thought it was normal age-related memory loss, since he was about 85!

Unquestionably, all of these simple exercises were very meaningful and could have been executed by us had we known what we know now. We assumed he knew those things. In retrospect, I don't remember asking Dad what day it was or to show him something and ask him to name it, or to ask him who is the president of the United States. Often, we watched the news together and he would comment on certain issues. Perhaps, if we had discussed the news with him,

we may have noticed the changes in his mental capabilities. But when I asked him to read clips of articles from the newspaper to me, he would politely decline.

Things that may seem small and insignificant like Dad holding the newspaper, moving his lips like he was reading, but didn't want to discuss it probably should have been a red flag for us. The apparent answer is that you really have to pay attention. This MMSE did clearly illustrate that every question and exercise meant something, and what had been familiar to Dad had surely been stolen by AD.

During the Early Stage, I strongly recommend preparing for the Middle Stage. Since there are no clear boundaries to these stages, you're much better off preparing for the adjustments before the first serious symptoms manifest. In my opinion, the Middle Stage is probably the most difficult because it is physically and emotionally demanding. Many clinicians suggest that driving should definitely be discontinued during the Middle Stage. Actually, regardless of the alleged stage, you must be the judge as to whether a patient's driving is safe or unsafe. Our dad began having little car accidents, but nothing involving another car, in the Early Stage. He just started running into things, which was very unusual for him. Thus, my brother and I decided that we better get him off the road before he had a serious accident. We were participants in having his driver's license suspended by the Department of Motor Vehicle during the Early Stage. Or what we thought was the Early Stage. We had to take the initiative since you really don't get much help deciphering these stages after the initial diagnosis from the HMO. They referred us to a support group, a nutritionist, and a social worker, who came out and assessed his home for safety, which we were already on top of.

We knew that taking away his driving privileges was going to be a big disappointment to Dad, so we orchestrated the announcement through his doctor. The doctor sent a notification about his driving ability to the Department of Motor Vehicle, which then requested that Dad come in to take a driving test. This way we avoided Dad getting upset with us directly for reporting his driving status. Dad immediately surrendered his driver's license. After taking care of that major detail,

his cars were taken away because the literature on AD warns you to move the cars or dismantle them because one day an AD patient's mind will tell them that they can drive and they will get in a car and try. Dad expressed such a sense of loss when he lost his driving privileges. He became very sullen. In our American society, driving is such a symbol of individual freedom and independence, especially for a man. Six months later, however, it wasn't even an issue.

The incident referred to in the Preface involving Dad not recognizing himself when he saw himself in the mirror on the second floor stair landing in my home actually occurred in the Early Stage, or what I thought was the Early Stage. Many clinicians report that the inability of AD patients to recognize themselves is a symptom of the Middle Stage. Upon researching this matter further, I learned there are no absolute indicators of a particular stage. For example, if a diagnosis is Middle or Moderate Stage, but a symptom manifested is relegated to Late or Severe Stage, this does not necessarily mean that the condition has progressed to a more advanced stage. It could simply mean that the symptom occurred differently in this particular patient.

Because of the gray areas in deciphering the stages, I recommend that you conduct your own research on the stages, explore clinical trial research, and begin to contemplate your positions on issues such as force feeding, resuscitation vs. non-resuscitation, and approving an autopsy on your loved one's brain after death in the Early Stage. It is important to remember that while there has been considerable progress in accurately diagnosing AD clinically, at this time an autopsy remains the only guaranteed determination of distinguishing AD from other dementias that may have impacted the brain. One never knows how much time there is between the progression of the symptoms, and one definitely doesn't know how long it is going to take to find a cure for or prevention of AD.

I didn't give much thought to the importance of clinical trials and their influence on me personally until my encounter with the impact of AD on Dad and our family. Recently, I learned on an upfront and personal level how extremely important clinical trials

are in the goal to prevent, treat, and find a cure for AD. Clinical trials are basically rigorous studies to determine whether new drugs are safe and/or effective. A drug must pass through three stages before approval, taking approximately 13 years to actually get approved. The cost is approximately \$860 million. Yes, \$860 million, to get a drug approved! I was dumbfounded when I heard this amount – no wonder drugs are so expensive. I am now a formidable advocate for participating in research studies and non-invasive AD trials, and urge everyone to get involved.

We had Dad assessed for a clinical trial in order to get more support from the professionals studying and researching AD and related dementias. I was pleasantly surprised to learn that some studies and trials offer a financial incentive for your time. But quite honestly, I was most interested in the added benefits of a clinical trial or study which offered things like memory testing, medical examinations, blood tests, brain MRI's, and other neuro-imaging tests, and at no cost to the patient or family. I rationalized that there was no point in exposing Dad to another exhausting MMSE unless he could possibly reap the benefit of receiving an experimental drug. Some of the challenging symptoms he was experiencing at the time were increased confusion, anxiety, and insomnia. To my surprise, again, it was determined that he didn't meet the criteria for many of the trials, mostly because of his age.

Currently the medications available to AD patients are considered symptomatic drugs, meaning they only treat the symptoms of AD and then they level out. In other words, these drugs can't prevent the onset of AD, nor can these drugs slow down the progression of the disease. There is a great deal of talk about a disease modifying treatment being discovered in the near future. This means a treatment that prevents or minimizes the disease itself – not just the progression of the symptoms of AD. In Dad's case, I have observed that the two medications he currently takes have probably leveled out. The doctors I have spoken to about this suggest keeping him on the drugs because they are not certain whether the symptoms of AD will become more severe even though the medications are probably ineffective now.

Numerous people are suspicious of clinical trials because they don't know what happens to the data or the real motivation(s) behind the clinical trial. Others are reluctant because of the potential impact it may have on them. And still others remember the past abuses and atrocities of such research studies and clinical trials. There are many safeguards, but you must investigate the regulation of clinical trials in your state. California law requires: that you must be informed about the nature of the study; the procedures in the study and any drug or device to be used; the discomforts and risks reasonably expected from the study; the benefits reasonably to be expected; availability of medical treatment should complications occur; the opportunity to ask questions about the study or the procedure; the ability to withdraw at any time and discontinue participation without affecting your future care at the institution; and be given a copy of the signed and dated written consent form for the study.

Information about the doctors conducting the study is also available to you. If you are interested in being evaluated for any type of dementia, including AD, or in participating in a research study or clinical trial, I suggest you locate an academic medical center in your state. There are approximately 55, including in Canada. Individual participation is crucial to the goal in finding a cure for AD. I mentioned earlier that AD is an equal opportunity disease. As a result of a conference I attended at University of Southern California in 2011 called "The Many Faces of Dementia," I am now aware that the majority of drug trials fail to meet recruitment goals, which directly affects the ability to meet the primary outcomes. Sadly, African Americans' participation in AD trials is very low, yet AD is projected to affect this population at a rate twice that of the Caucasian population.

I must admit that I was and continue to be a bit hesitant about participating in any medically invasive clinical trials like drilling in my head or a lumbar spinal tap, while I'm alive. A brain autopsy, on the other hand, I have agreed to for myself. The authorization is on file with the organization, and the instructions will be added to my will and living trust. A brain autopsy for AD involves removing

the brain at the time of death to examine the tissue for plaques and tangles only associated with AD. There are many types of dementias and performing a brain autopsy is the only way to identify which dementias were present and is currently the only way to prove that the initial clinical diagnosis of AD was accurate. Further, a brain autopsy could be revealing and edifying for family members who may be concerned about genetic links to the disease. (*See Question #3 Are You At Risk for AD?- Chapter 2*)

It is for this reason, I would like my father to undergo this procedure also for posterity. Unfortunately, for personal reasons, my brother does not want an autopsy performed on him or our father. This is a poignant example of personal differences that can occur between primary caregivers and family members. Equally important is the fact that the discussion of this issue is occurring now and will continue. My essential point is that I recommend research, discussion, and consideration about these types of serious issues in the Early Stages rather than initiating discussions in the Later and Terminal Stages.

Lastly, if you haven't made any legal plans involving advanced directives such as a living will or a durable power of attorney for healthcare, or trusts, executed before the diagnosis of AD, I advise that you definitely consider legal and financial planning in the Early Stage. Quite frankly, I am suggesting right after the diagnosis is made. This includes authorizing another person to make healthcare and financial decisions for you or the AD patient. It is possible that you could get into issues of *legal capacity* after the diagnosis.

In this case, *legal capacity* means the level of mental functioning necessary to sign official documents. Generally speaking, if an individual with AD has sufficient cognitive ability to understand the meaning and significance of a legal document, he probably has the legal capacity to execute it. An attorney can help determine the level of legal capacity required to execute since the level of legal capacity required may vary from one document to another. In this case, making sure you have an attorney who has the AD patient's best

interest in mind is critical. Our dad clearly does not have legal capacity to sign any official document, but he has a living trust that was executed years before his diagnosis and updated after his diagnosis.

Ideally, the best case scenario is for AD patients to educate themselves about the range of medical care available when making decisions to use, withdraw, limit, or refuse treatments before the need to make end-of-life decisions, normally in the Terminal Stage. It is actually more palatable for everyone involved, including healthcare providers and family members. It isn't easy initiating any of these types of discussions, but it is better early in the game rather than later when you feel pressured and under emotional coercion.

MIDDLE STAGE

A whole new ball game, most of the plans that worked in the Early Stage will have to be adjusted. Many clinicians report that this can be the longest stage, lasting from two to ten years. The difficulties with memory loss become more obvious, to the point of interfering with the AD patient's daily living activities. In this stage, the parts of the brain that are robbed directly affect how a person acts, walks, goes to the bathroom, finds their way around the house, and gets dressed.

Changes in some patients' personality become evident by their behavior, such as cursing, hitting, and pushing. For instance, there was an incident involving a physical therapist who was providing his services to Dad. One day, the in-home-care agency that contracted the therapist's services called and reported that the therapist wouldn't be returning to Dad's home because Dad had shoved him. Knowing Dad, I found that allegation to be preposterous. I immediately went over to Dad's home to ask him about the incident. He told me that he had accidentally bumped into the therapist after he had arrived late, entered the front door, and rushed past him.

The expression on his face when he said that he had "bumped" into the therapist confirmed to me that Dad had shoved this man. I could not begin to imagine it! Our dad, a kind, gentle, non-violent

89-year-old had shoved this man! After discussing the matter with Dad, it became apparent that he resented the therapist coming late, entering his home without benefit of an apology, and just trying to rush pass him. It appeared that Dad felt disrespected by this man in his own home, did not like it and expressed it physically. In addition, there were incidents when our father, whom we had never known to curse or use profanity, would now occasionally say “damn” or “hell.” These were new behavioral responses to situations that Dad had never exhibited. I am now aware that personality changes are common with AD patients, involving physical and behavioral changes as well as verbal ones.

Point of fact, on numerous occasions when Dad has been admitted into the hospital, he has become outraged. I can only assume that the unfamiliarity of a hospital setting, with different nurses coming in and out, is very disorienting. I believe he becomes fearful in these circumstances. In the hospital room one time he asked, “Who are these people in my house?”

I’ve observed the nurses telling Dad what they want him to do, but I could see that he didn’t understand. I wondered why they didn’t know that he was diagnosed with AD. Aren’t his records in the computer? During these ER visits I’ve observed nurses and doctors constantly reading and imputing information in their computers. On second thought, perhaps they did know Dad’s mental status, yet lacked knowledge and training to deal with it appropriately. Still, from their perspective, they had a job to do. They needed blood, urine, and x-rays. Dad’s emotional display of anger seems to be triggered when he lies in the hospital bed – a strange place, around strange people – and is experiencing discomfort. He actually displays behavior indicating that he is very confused and disoriented. Often he has had to be restrained because he was pulling out the catheter and other intravenous tubes, which is very painful. Restraining him only infuriated him more. He raged, yelled, eyes filled with tears, and at times said cruel things to me and my brother, as well as to the nursing staff. I can only assume that the poking and prodding on him in the hospital must trigger some awful memories.

I should add that women can be just as contemptuous. A friend once shared that her mother-in-law was an AD patient. On a few occasions, she has shocked the family members by cursing at them, leaving them in a state of disbelief. This little lady had been such a soft-spoken, mild, meek, respectful, church-going woman who never cursed prior to the disease.

The moral of this story is that you can't take the AD patient's behavior personally. It is the disease that is responsible for them acting out as they do.

Tough choices must be made during this Middle Stage. Some form of 24-hour care must be arranged. Are you going to move in with your loved one? Are you going to move your loved one in with you? Are you going to move your loved one to a nursing home or convalescent home? Are you going to provide 24-hour care for your loved one in your home or theirs? Caregiving is now required to structure and supervise the patient's daily activities, as the memory loss has now begun to steal the patient's ability to manage basic daily self-care activities. Many require prompting and cuing for all activities such as eating, bathing, dressing, walking and sitting. Someone must definitely manage the loved one's financial affairs.

There are severe changes in the short-term memory during this stage. We noticed that Dad no longer showed an interest in reading the morning paper, an activity he had enjoyed for years. Further observation reflected that Dad didn't appear to be able to read any longer. He didn't seem to recognize the words. He used to call me on the telephone almost daily in the earlier stage. Now he is unable to dial phone numbers, and often is unable to hold the phone properly to his mouth and ear without assistance. He needed to be told to brush his teeth and wash his face every morning and evening. Prior to this stage, these activities were automatic for Dad. I remember being at my father's house one day and listening to the caregiver give him some instructions while assisting him to dress. Dad looked at me and said in a very apologetic tone that what she was saying was "*just words*". I knew that was his way of saying that he didn't

understand what the caregiver was saying. Although her instructions were simple and clear to me, Dad didn't comprehend. Hence, it was obvious that the progression of the disease now required that the caregiver assist him with getting dressed much more than before.

Additionally, serious changes in Dad's long-term memory were his inability to recognize and to remember most of his old friends and acquaintances. In fact, he no longer recognized family members like his daughter-in-law, granddaughter, grandson, great grandsons and great granddaughter, and other extended family members. Sometimes he didn't even remember that he had a daughter and son, but ironically, he did remember our names. Currently, he rarely says our names.

LOST

There are studies that report that about 50 percent of AD patients become clinically depressed. Of course, many doctors simply recommend anti-depressants. Ironically, our father's intermittent episodes of feeling lost didn't seem like depression to me. Although he appeared sad when he spoke about feeling lost and feeling like something was seriously wrong with him, it was not clinical depression. My brother and I told him that he is strong and healthy and doing fine, but that his memory was getting very bad and he was very forgetful. We continue to assure him not to worry because we're taking care of everything. Although it is the best we can tell him, it appears to help him feel better, at least for the moment.

One day I discovered a poem and it was another defining moment for me. It became very lucid to me that my brother and I didn't have a clue as to what "lost" really meant to our dad. I believe this unknown author really captured and conveyed the deep sense of "lost" Dad may be feeling from time to time, but is unable to convey or articulate to us due to his irretrievable memory and vocabulary.

Do not ask me to remember.

Don't try to make me understand.

*Let me rest and know you're with me.
Kiss my cheek and hold my hand.*

*I'm confused beyond your concept.
I am sad and sick and lost.
All I know is that I need you
To be with me at all cost.*

*Do not lose your patience with me.
Do not scold or curse or cry.
I can't help the way I'm acting,
Can't be different even though I try.*

*Just remember that I need you,
That the best of me is gone.
Please don't fail to stand beside me,
Love me 'til my life is done.*

~ Anonymous

Dad no longer remembered that he had been a career fireman and that he and his wife had traveled the world. Albums of pictures cease to prompt his failing memory. Dad had increasing bouts with fidgetiness, getting up at night and walking around the house, and sometimes even attempting to get dressed for work. Consistent with the research and literature on AD, we have experienced many of the symptomatic behaviors such as agitated behavior, suspicious or accusing behavior, aggressive behavior, hallucinations, repetitive behavior, and some wandering – all of which we learned to manage. They have all been manageable once we learned how to identify the triggers and then try to avoid them.

Driving should definitely be discontinued during this stage if it hasn't been restricted already. Restlessness and distress known as "sundowning" may occur, as well as catastrophic reactions to insignificant events. Cognitive functioning is greatly impaired during this stage and urinary incontinence often becomes an issue.



ADVANCED STAGE

In 2011, I began to realize that Dad was really in the Advanced Stage, which is often referred to as the Late Stage by some clinicians. Ironically, this corresponds to the score of 6/30 assigned to him after the MMSE assessment in 2010. He was evaluated and rated “severe cognitive impairment.” At this point, reportedly many patients rely on the caregiver(s) for total emotional and physical support, and fluctuating levels of awareness become apparent. I remember, one afternoon my father and I were sitting outside on a bench placed on his front porch so he could see and speak to the neighbors and observe what was going on in his neighborhood. I found that sitting in the backyard, even with a pool, wasn’t as stimulating as sitting on the front porch. As we sat, Dad commented on what a nice day it was and what a nice neighborhood and house this was. Then he turned to me and asked if this was my house. At the time it just seemed incomprehensible that he didn’t recognize his own house. This was the home he has lived in for almost half a century. Equally significant, it is the home that he very poignantly stated that he wanted to remain living in.

I’d been down this road of incomprehensible disbelief before, so calmly I replied, “Dad, this is your house. You probably don’t

recognize it sitting up here on the porch. You and Mom purchased it almost 50 years ago. It's a great house. There are lots of fond memories here. You own it! What an accomplishment! You are such a wonderful provider." My goal was to make him feel successful. Praise is a good defense against feelings of embarrassment, hopelessness, and low self-esteem because of severe memory loss. If faced with such a situation, redirecting the AD patient's attention after responding to their questions or statements in a positive way can be very helpful.

Some of the other symptoms that became pronounced during this stage are that Dad laments that he feels mixed-up and there are increased expressions of feeling "lost," and that he doesn't know what's going on. Often the caregiver has called me to assist her in explaining to Dad whatever it is he is agitated or confused about. On those occasions I've talked to him on the phone or have rushed over to his home only to find out that he will have forgotten those negative feelings and say that he feels fine. Closely related, there are increased episodes of Dad saying he wants to go home when he is already in his home. On one occasion, my brother took him to his bedroom thinking the familiarity of his bedroom would help him realize that he was in his home. Dad only responded by insisting that he'd never been in that room before. Still another occasion, I recall one evening when it began raining very hard and the sound of the rain began to annoy him. Dad asked me to turn off the noise. He didn't recognize the sound as rain! Repeatedly, he requested that I stop the noise. I tried to explain that the noise was actually rain, an act of nature, but to no avail. Finally, I assured him that the noise would stop on its own, and suggested that he take a nap. He did and when he awoke the rain (a.k.a. noise) had stopped.

Reminiscent of a baby, Dad often tries to put things in his mouth, and we have learned to handle this with compassion and sensitivity. The clinical term for this is *hyperorality*. There's a decreased ability to distinguish what is food and what isn't. For example, when you request Dad to extend his hands in order to put lotion on them, sometimes he will attempt to lick the lotion off his hands. As care-

givers we have to keep an eye on him at all times, just as you would a toddler, for his safety. There are many references in the literature stating that in this stage AD patients require external sensory cues to perform repetitive one-step activities like combing or brushing hair, brushing teeth, and dressing.

Consistent with the literature, we are experiencing that Dad needs to be told what to do for everything. When he wakes up in the morning, he lays in the bed until the caregiver comes into the bedroom and prompts him to get up. Every morning he has to be directed to brush his teeth and to wash his face. Often when he gets in and out of a car, he has to be instructed to put his foot in or to put his foot out of the car. Some days he needs more prompting than others. Dad's muscles and joints are becoming rigid. I've noticed that often times he stands with his legs bent at the knee. Another example is if I give Dad a book or put something in his hands, when I remove the object from his hand, his hand remains extended. He has to be told to put his hand down or I have to close his hand and place it somewhere for him. These types of incidents have left me wondering whether the brain is failing to instruct Dad to move his hands or legs or whether it's physical limitations. I think it is both.

Supervision and physical assistance is now required for personal activities, such as toileting and personal hygiene. Urinary and fecal incontinence have increased. Language and comprehension skills as well as fine and gross motor skills are severely impaired. Rarely does Dad initiate conversation; however, he tries to respond when spoken to. On many occasions his responses are rambling and incomprehensible. Chewing, swallowing, and eating problems may develop, leading to severe weight loss, during this period. Instead, our dad gained weight, requiring the need to have his slacks altered. This disease is so insidious! On good days, Dad is significantly aware of his environment. One day at church, I told Dad to sit down while the rest of the congregation stood. I observed Dad turning around in his seat and looking around the church. Then he asked, "Why am I sitting and everybody else is standing?" This statement reflects critical thinking skills and conveys awareness of his surroundings.

TERMINAL STAGE

This is where the rubber meets the road. The patient is totally dependent on others. Aspiration pneumonia, bedsores, and other serious medical challenges are very common during this stage. My recommendation again is to research and determine your position on issues such as force-feeding, resuscitation, hospice care, and autopsy. The inability to remember how to swallow is another dangerous symptom. This failure can bring on an onslaught of other complications such as dehydration. The inability to eat is another result of not being able to swallow, causing vitamin and mineral deficiency, weakening the immune system, and can cause asphyxiation. Mysteriously, in this stage, the mind fails to instruct the body on how to accept and breakdown nutrition, so intravenous feeding is often suggested.

In this stage, you will definitely have to come to terms with your opinion on comfort care or life prolongation. There is significant evidence to support the fact that foregoing fluids and nutrition in end-stage illness does not cause suffering. However, providing nutrition artificially frequently causes unpleasant side effects, such as bloating and aspiration pneumonia.

Comfort care, on the other hand, means palliation only such as easing or soothing a patient. This excludes artificial nutrition, dialysis, and all other medical interventions unless necessary for the control of the pain and discomfort. If or when our dad becomes mute, bedridden, incontinent of bladder and bowel, has immeasurable intellectual functions and death is inevitable, we have decided that comfort care is the desired goal for him. That's where hospice care could be feasible for many AD patients. It is available for Medicare patients with terminal diseases when the anticipated survival time certified by a physician and a hospice director is six months or less. With that said, I believe many patients still respond to the power of touch, the power of soothing words, music, and prayer. In similar circumstances, what will be the decision for you or your loved one – comfort care or life prolongation?

My description of each of the stages is brief and general because I don't want readers to become obsessed with all the symptoms listed. Rather, the purpose is that you be informed and knowledgeable so that you can make informed decisions. It's imperative that you understand that each patient is different and his or her AD experience is unique. As I keep mentioning, symptoms vary from patient to patient. I suggest that you read the medical journals for more specific information on the stages and their accompanying behaviors, and consult with your healthcare professionals. Armed with some general information about the changes that may occur, you are now ready for our assessment components and to develop a personal care plan for you or your patient.

CHAPTER 6

HOW TO DESIGN YOUR PERSONAL CARE PLAN



I was focused and worked very hard to develop a care plan that would work specifically for Dad, addressing all those things unique and special to him and circumstances in his home, which we now refer to as his Personal Care Home. It was essential that his personal care plan was totally personalized exclusively for him. We call it a *Personal Alzheimer's Disease Care Plan*, herein referred to as PADCP.

In an effort to make the care plan easy to grasp for everyone, I worked equally hard in devising assessment components to guide you in designing your patient's plan. The following are the assessment components, based on a strength-based plan developed for our dad's PADCP, and for your use as an in-home-care prototype:

ASSESSMENT COMPONENTS FOR IN-HOME-CARE

- The life course or cycle of the patient (for example, a brief biographical sketch, reviewing photo albums, interviewing significant relatives and friends).
- A patient's strength assessment integrated with their daily activities.
- A family strength assessment.
- An in-home-care assessment if you require providers. (I've dedicated a whole chapter to this component later.)

THE PATIENT'S LIFE COURSE

An understanding and assessment of a patient's life history is fundamental because it gives foundation for the PADCP development. For example, in 1994, I conducted a biographical interview with Dad for an adult development class in a master's degree program I was pursuing. I believe that it is revealing to observe how Dad's life course influenced his adaptation and ability to navigate AD, and my ability to develop his PADCP. I believe my overview of the primary influences in our dad's life will help to guide you in identifying the unique influencing factors in your loved one's life as well.

This is not a difficult task. You can conduct a taped interview, or if you have shorthand skills, record it by written word. Either way you may find as I did that your loved one's story was a story waiting to be told. Dad's story is interesting and intriguing, a testament to the manner of man he has always been and is now, even as he faces AD. He and I enjoyed every minute of the interview as it gave him the opportunity to share his life experience with me in a way he had not done before. I hope that you enjoy it as well and find it inspirational to do the same with your loved one. Most importantly, it will provide a direction for you to take in developing your patient's PADCP.

BIOGRAPHICAL SKETCH AND LIFE CYCLE OF MR. WINCE VANDERBILT KING, JR.

Our dad, Wince Vanderbilt King, Jr. was born in 1919. His parents moved to Los Angeles, California in 1923 in pursuit of better opportunities for their family. Dad had one sister, seven years older than him. He attended the neighborhood elementary, junior high, and high schools. In 1936, when he was 17, he and some classmates formed a social club called the Royal Syndicators. This club became a major influence in his life.

Upon completing high school, he received a full basketball scholarship to attend college in another state. This was the first time he had ever left his family. He recalled being recognized as an outstanding

basketball player and winning two All Conference Championships the three years he was in college. During his collegiate tenure, he converted to Catholicism, which became the foundation for his life and grounded him spiritually. He was a devout Catholic, attending church every Sunday and Holy Day. He didn't graduate from college. Instead, he returned home to marry his high school sweetheart, our mother, Marguerite. They married in 1941 when Dad was 22. His marriage became a foundational driving force and significant factor in his life.

A year later in 1942, at the age of 23, Dad was drafted into the United States Army. He spent 15 months in India, where he experienced overt discrimination by Americans who were serving with him in the army. He described his tenure in the army as a downside of his life.

Four years later, in 1946, I was born, and 18 months later in 1948 my brother was born. Dad joined the Los Angeles Fire Department in 1947 after passing grueling agility tests. You know firemen are physically fit men, and Dad prevailed. Dad's health and physical strength is another key element in his life. At this time, Dad also purchased the first home for his family, where we resided for 17 years.

For nine years, Dad was assigned to one of the two segregated fire companies. For the sake of posterity, the black firemen agreed to separate and demand integration. In 1956, under pressure from political and social organizations, the Los Angeles Fire Department caved in and integrated the stations. These brave black men paid a tremendous price on so many levels: emotionally, psychologically, physically, and socially. Such experiences had to cause excessive stress.

The personal sacrifice of Dad and the other black firemen resulted in them being physically isolated, excluded from activities that the other firemen enjoyed and overall-emotionally and psychologically abused in their integrated stations. Can you imagine putting your life on the line in fires while working with men who are openly hostile to you on a daily basis? The overt racism wreaked havoc on the mental and emotional well-being of many of these black firemen, yet our dad endured.



Firemen at one of the two segregated stations they were allowed to work. Dad is the first man to the far left.

No white fireman talked to our Dad for the whole 24-hour shifts he worked for seven years. All of the other black firemen faced the same treatment. My Dad recalled that what got him through this ordeal and those grueling years were his strong belief and faith in God, and his

dream to be a good provider for his family. The black firemen, though physically separated by their stations, remained emotionally, spiritually, and socially united. They began a tradition of coming together at least once a year for an annual Christmas party held in our Dad's home. This commenced in 1947 and prevails to this day in Dad's home, even though all but two of the original black firemen are deceased. Today, one of the two segregated fire companies that Dad served at has been converted to an African-American Fireman's Museum as a testimony to their struggle.

My brother, a retired captain in the Los Angeles Fire Department, now continues to host the annual Christmas party in honor of Dad's tradition. Yes, the torch was passed on. The personal sacrifices made by Dad and the other black firemen were not in vain. I should mention that the Royal Syndicators Social Club celebrated its 50th Anniversary in 1986. They disbanded in the mid-'90s because of the demise of the members. Our dad is the last standing member of the club at 92 years of age.

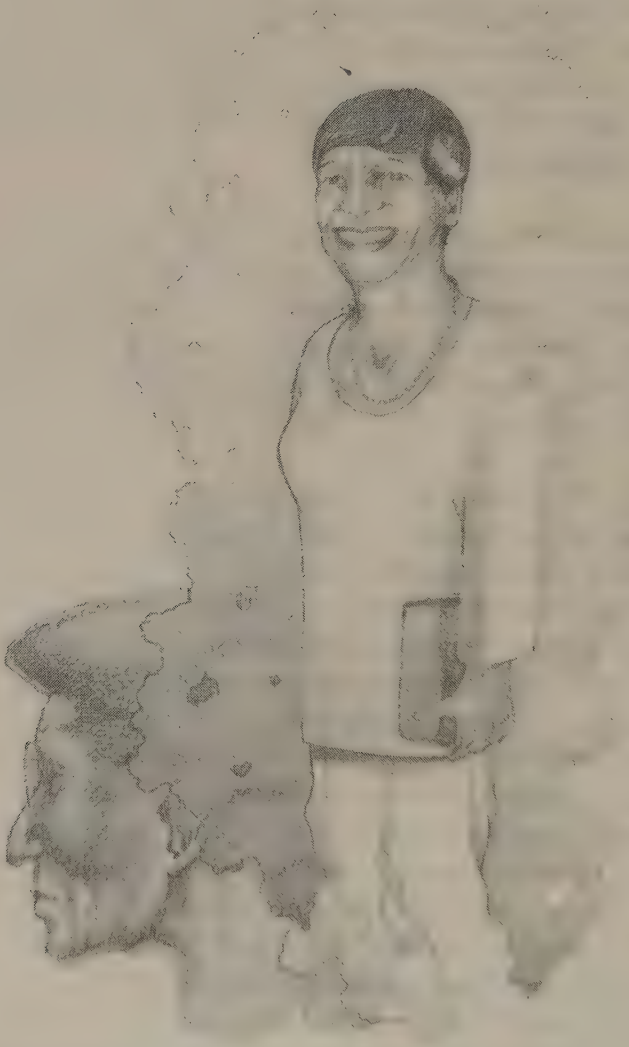
As a result of Dad's flexible schedule as a fireman, he took on a second job as a skycap at Los Angeles Airport. This skycap business was founded by one of Dad's friends in 1956. He worked part-time at the airport on his off days until he retired from the fire department after 25 years of service at the age of 53. While working both jobs, in 1964 he purchased another house, which is the current home that he continues to reside in, and comfortably I might add. In 1989, after his retirement from the Fire Department, he began working full-time at the airport and continued until he retired after 33 years of service at the age of 70.

Dad recalled being a little hesitant about total retirement for fear that he wouldn't know what to do with himself. But to his surprise and ours, he adjusted very well. He kept himself busy and remained active. He helped Mom out with household chores. They focused on living a healthy lifestyle, including eating more healthy foods. Dad exercised a minimum of three times a week in his home gym on his Solar Flex, the Nordic Track, and the Schwinn Airdyne Bike. He

washed and maintained the cars. He enjoyed driving to his favorite mechanic to talk about cars. He loved watching the NBA and NFL games, as well as banter about them. He also enjoyed playing cards with Mom. They continued to attend church every Sunday and Holy Day. They never stopped traveling internationally, preferring cruises in the latter years. They attended a variety of social affairs and entertained friends in their home. He read the newspaper, the Bible, and magazines that he subscribed to like *Sports Illustrated*, *National Geographic*, and auto magazines.

Our mother's death in 2000 impacted Dad's life tremendously. They had been married for 58 years, and they did almost everything together. Her death left a huge empty space in his heart and a void in his life. Dad has remembered the name Marguerite long after he forgot most other significant names, like those of his son and daughter.

On one occasion, I visited Dad's home and while standing on the porch after ringing the doorbell, I heard, "Marguerite, Marguerite, get the door!" Dad called out. The caregiver, said, "Okay, I'll see who's ringing the doorbell." At that time, Dad's wife, Marguerite, our mother, had been deceased for approximately ten years. They had lived happily in this same home for about 36 years. So far, AD had robbed our dad of everyone's name except Marguerite. She still remains in his mind. When this episode and similar ones occurred, my brother and I tried to delicately orientate Dad to the reality of Mom's death. This only shocked him and he would angrily respond with a statement like, "I didn't know" or "nobody told me." He would look so distraught and I would simply walk away with a feeling of agony. It really hurt me that each time it seemed that we had caused Dad pain. He had no recollection of Mom's death and obviously he remembered her. So our informing him of her passing only tormented him. And there were numerous incidents reported by our caregivers that Dad would wake up in the middle of the night calling out for Marguerite.



Finally, desperate to relieve Dad's pain, our distress, and the caregivers' inquiries as to what to say when Dad calls them Marguerite, or calls out for her, I consulted an AD clinician as well as researched

the issue. I learned that being in the “*now*” with a patient is not just a term of serendipity. It really means being in *their* reality. Since the patient cannot remember the reality of the current situation, we protect them, their psyche, by honoring their reality, which is whatever they feel *now*. So the caregiver who responds to Dad in a positive way when he calls her Marguerite gives him peace and solace. We don’t tell Dad that Mom is dead any longer. We just say that Mom is not here right now or that she’ll be back. And guess what, he forgets to ask about it until the next episode.

Current observations now are that Dad doesn’t ask about Marguerite anymore. And interestingly, even though he doesn’t recognize pictures of her or the two of them together scattered throughout the house, her name still is embedded in his mind. Recently, in March 2012, Dad had a conversation with our in-home-caregiver, whom he refers to often as Marguerite.

On March 6, 2012, the in-home-caregiver, called me at home and told me that Dad had made her cry the day before. My heart skipped a beat. I thought, oh no, we can’t lose her. “What happened?” I inquired, trying to sound composed. She said after Dad had eaten dinner, she washed the dishes and then assisted him to his recliner chair in the den. The caregiver said Dad looked very peaceful and content and calmly he said, “Yes! Yes! Yes!” She said she looked at him and said, “What’s going on Mr. King, what’s on your mind?” Dad began a monologue that she said brought tears to her eyes. He began by saying, “Life is good. Life has been so good to me – to us. You know one day I’m going to die.” Not sure of where the conversation was going, she interrupted him and asked, “Mr. King, why are you saying that? Are you okay?”

To her surprise, he answered succinctly and articulated, “Because it’s true. I am going to die someday. We can’t live forever. But I want you to know that I have taken care of everything. You won’t have to do anything. You won’t have to worry about anything. You will be well taken care of, Marguerite. I’m older than you so I might die before you. And I just want to thank you for being in my life. No one

is perfect, but I can't think of anything, not anything, you have done wrong to me or our family. You have been a good mother and a good wife. You've treated me so good and I thank you for that, and don't worry. We will be together again one day. Now come over here and give me a kiss, baby." She said he chuckled a bit, and with tears in her eyes, she got up and went over and gave Dad a big hug.

The caregiver described herself as being speechless for the first time in her life. She was accustomed to Dad calling her Marguerite, his deceased wife's name, but this was different. The tone, the gentleness in his voice, the expressions of gratefulness, along with the clarity and the length of the monologue, was simultaneously beautiful and mind-boggling to her. Conclusively, Dad's caregiver said she was left wondering what triggered that beautiful expression of love to the woman he had been married to for 58 years at the time of her untimely death.

Similar to the caregiver, I was stunned hearing this story and speechless as well. I asked her to write what she had just told me, which she agreed to do. When I hung up the phone, I just sat there and contemplated how mysterious the symptoms of AD were. Some days Dad's speech is confusing and rambling and he can barely enunciate his words, and other days his speech is short with clear responses and statements. And then comes a day when a spontaneous expression that is seemingly lucid, spoken with clarity, and almost mystical occurred. March 6, 2012 was definitely a hallmark for Wince King's spoken words since the onset of AD, to date.

Think about it! Since Dad can't remember Mom's death, the reality of telling him that she died is only mentally and emotionally traumatizing to him. After a long tedious explanation or even a simple statement, he won't remember later. Numerous times we have taken Dad along with us to place flowers on Mom's mausoleum. On one occasion, whatever Dad felt when he saw the mausoleum with Mom's name on it resulted in his legs buckling and him visibly becoming weak and shaken. This could have just been a bad day for Dad, but we no longer take Dad to Marguerite's mausoleum. Overall, Dad has adapted

relatively well to Marguerite's absence because of his sheer tenacity and determination, good temperament, and his faith and hope in God. But gone are the fond memories of our dad's life that he described as a "beautiful life." Gone is the memory of his 50th Wedding Anniversary Mass and Candlelight Dinner and Dance in 1991, attended by 191 of Mom and Dad's friends. It was a night that Dad described as the "highlight of my life" during the interview in 1994.

Finally at the end of the interview, I had to ask Dad about his feelings on impending death, whenever that occurs. He said, "If I were told that I was going to die this evening, I wouldn't feel cheated. I'm 75 years old and 90 percent of my life has been beautiful. My family and I have a strong love for each other." It became apparent to me that the same sense of integrity and dignity in which Dad lived his life, he will exemplify in the process of dying.

Anxious to see how Dad's life cycle played out in developing his personal strengths, the next step was to assess his strengths and needs in order to remain in his home with 24-hour live-in-caregivers. As mentioned earlier, initially Dad did not want strangers living in his house. However, due to the progression of the disease, he began to realize that he needed help and eventually expressed his appreciation for the help that was provided because he wanted to remain in his own home. Dad also constantly expressed a strong desire to cooperate and do whatever was necessary to get along. In fact, that was one of his mantras: "I just want to get along." I really believe Dad has an uncanny awareness in that he realizes the importance of cooperating and getting along with the caregivers so that, in turn, they will take good care of him. Innately, he understands the importance of this and it works for him and the caregivers.

THE PATIENT'S STRENGTH ASSESSMENT

Physically, our father continues to be a very strong man, thanks to the athletic background he honed while in high school and college, serving in the army, as a career fireman, and his love of exercise. He had no serious medical problems that weren't stabilized with medi-

cations. In fact, he was 90 when he had a serious head-neck surgery that he came through physically with flying colors. His home was large enough to comfortably accommodate a live-in-caregiver, and financially, he could afford reasonable fees of about \$3,000-\$3,200 monthly. I think it would be sacrilegious not to mention our father's strong spiritual beliefs as an excellent motivator for his ability to thrive during these health related challenging times.

The intention of this component is for you to identify, assess, and incorporate your patient's interests, strengths, and daily living activities from their life course into the development of their PADCP. Be aware, you will have to continually modify these activities as the disease progresses in order for the patient to successfully navigate the challenge of AD with dignity. Use the foundation of a strength-based concept to identify your patient's strengths for their PADCP. Focus on what he or she can still do, and *not* on what they can not do. As a guide for you, some common questions and concerns regarding the patient's current daily living activities that should be considered are:

1. How does the patient spend their time each day?
2. Does the patient exercise or go to the gym?
3. Does the patient go to church?
4. What are the patient's favorite subjects to talk about?
5. What are the patient's hobbies?
6. What are the patient's favorite TV shows?
7. What is the patient's style of dress?
8. Does the patient take naps?
9. What is the patient's bed schedule and morning wake-up schedule?
10. Does the patient take a bath or shower daily, and what time of day?
11. What are the patient's favorite foods?
12. What are the patient's least favorite foods?
13. Does the patient like snacks?
14. What time does the patient normally eat breakfast, lunch, and dinner?

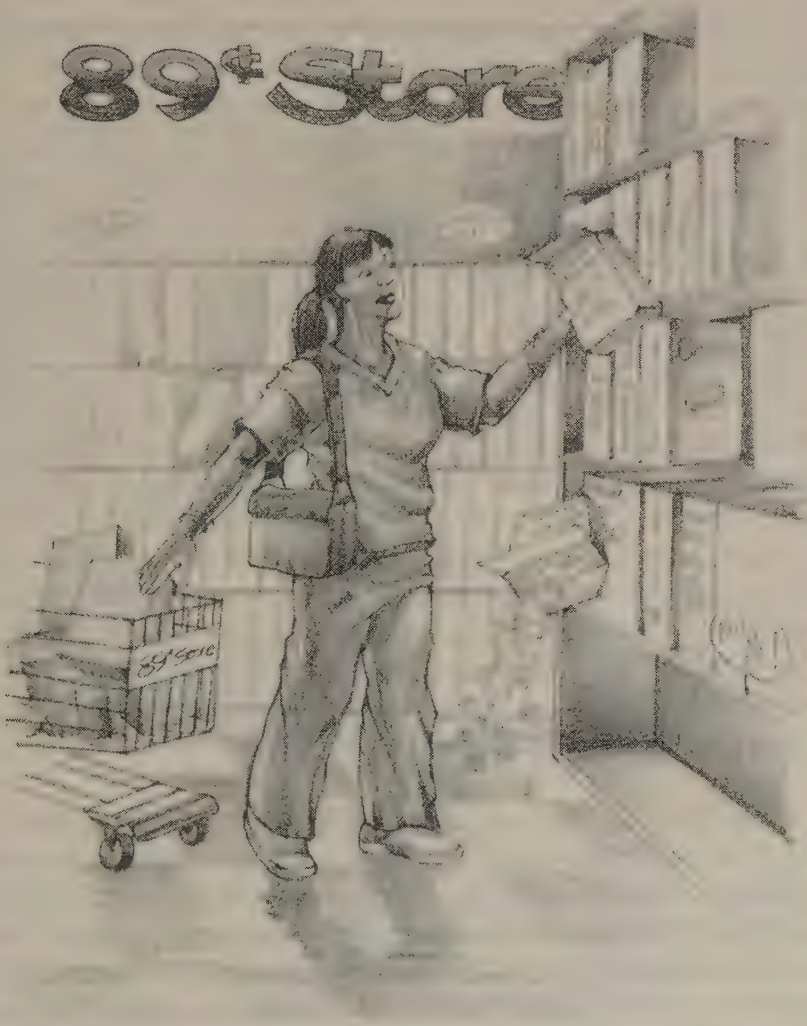
Dad was 84 when he was diagnosed with AD. That was four years after our Mother's death. He was living alone in a home that he had resided in for close to 40 years. There are precious memories associated with his home – photos capture some, and others are captured in awards and trinkets. Most of his friends were deceased or very ill. Nevertheless, I was able to identify the following personal strengths, features, and interests in his life cycle that currently are part of his daily living activities and could easily be integrated into his PADCP:

- First and foremost, Dad enjoys his home and is adamant about remaining in it. He appears to enjoy the comfort of his home. He rigorously climbs 16 stairs to enter and exit his home.
- Basically Dad is very cooperative; however he doesn't initiate any activities on his own. Yet, when an activity is suggested and is encouraged by the caregiver, he will try to participate in the activity. He is sociable and socially appropriate most of the time. He has a good sense of humor, a great smile, and a hardy laugh.
- Physically, emotionally, and spiritually, Dad is a very strong man. Because of his athletic history, it is important that he continue his pattern of exercising daily: riding his stationary bike, doing his hands, arms, and leg exercises, walking up and down the 16 stairs to enter and exit his home.
- Depending upon whether or not Dad has rested well the night before, he should continue to attend church on Sundays.
- Dad has always been a sharp dresser. He wears suits and nice sports jackets to church on Sunday. During the week, dad dresses casually, predominantly in activewear. He should continue to dress himself with assistance.
- We have instructed the caregivers to let him do what he can do – no matter how long it takes. For example, he continues to wash his face and brush his teeth and tie his shoestrings.

- Most of his hobbies included our mother, such as board games and cards. We have stimulated his interest in playing checkers and he plays pretty well some days. You can actually see him contemplating his moves. We have encouraged caregivers to play checkers with him for as long as he can. In fact, playing checkers has become a weekly activity that he and my brother share.
- His interest is waning in sports, including basketball and football. If my brother or the caregiver looks at these programs with Dad and talks about the game, he can become engaged.
- Dad enjoys going on some type of daily outing. He has the tendency to nap a lot when he just sits and is bored. So the challenge is to keep him busy.
- Dad always had good hygiene, bathing or showering daily. Currently, he still showers daily. There was a period during the earlier stages of this disease when showering daily was a challenge. We were able to overcome this. He is able to wash his face and brush his teeth. Sometimes he may require assistance.
- We are currently in the process of changing Dad's meal schedule. We think it's healthier for a patient Dad's age, 92 years old, to switch the lunch meal with the dinner meal. This way Dad will have the heavier meal in the early afternoon instead of the evening. This is good for digestion. Dad's morning wake-up schedule and bedtime schedule is a bit flexible. We try to keep Dad up as long as possible in hopes that he will sleep through the night. If he sleeps through the night, he normally wakes up about 9 a.m. When he awakens, he waits for the caregiver to come into the room to tell him to get up and start his day.
- Dad feeds himself. He has always had a healthy appetite, and he still does. Caregivers are amazed at his food intake. We are trying to get caregivers to keep his diet healthy. Dad has actually gained weight, yet he still maintains his athletic physique. He also enjoys eating out at restaurants.

- Our mother always prepared three healthy meals a day for Dad. He still expects breakfast, lunch, and dinner, which he should continue to receive.
- Dad enjoys snacks during the day. We have requested nutritious snacks and fresh fruits. We use snacks as a reward some days when he has anxiety issues.

(Note: part of the PADCP is adapting to the ongoing change.)



Healthy, nutritious meals are best for all people and especially for an AD patient. If you employ a live-in-caregiver or a caregiver that does grocery shopping for the patient, do not assume that they shop at the same stores, or eat the same things, or know how to cook the same foods you desire your loved one to eat. You must train them and patiently show them how you want the meals prepared. That's why it's important to hire a caregiver who is open to being taught new things.

Observing that some caregivers think they know everything and resent being told or instructed another way, a primary caregiver should not feel intimidated about expressing their desires regarding their patient or loved one. For example, the illustration on the previous page portrays a caregiver shopping at the 89-Cent Store for groceries. We want our father to eat fresh foods and vegetables. I do not want him eating large quantities of canned foods largely due to the sodium content. To insure that food is purchased from the stores we prefer, we now purchase gift certificates in the amounts to cover the groceries at those stores. It is a way to direct caregivers to the store of our choice, as well as to determine the amount to be spent directly on food. When our grocery list included food items that the caregiver is not familiar with, for reasons still unknown to me, many caregivers will not tell you. Therefore, you must be skilled in reading minds sometimes, and offer to show them how to cook various items or those food items will just rot in the refrigerator. I suggest that you simply incorporate a shopping trip with the caregiver as part of their orientation. You can take them to the stores of your choice and point out particular brands you prefer such as bread, oatmeal, and other packaged foods and produce.

The same goes with cleaning the house and cleaning clothes. Caregivers using the wrong household cleaning items because of the unfamiliar materials and types of natural woods or stone surfaces have destroyed floors and furniture pieces. I can't tell you how many clothing items (cashmere, wool, silk, etc.) shrunk because they were washed instead of being sent to the cleaners. Would you believe that a man's 100 percent gabardine wool suit was washed

and put in the dryer, as well as a wool cap? You must show them the appropriate cleaning items for furniture. You must show them how you want the beds made. You must show some how you want your loved one dressed; For example, in matching clothes and socks. For these reasons, I have become a big advocate of hiring a person for a probationary period first. This allows you to observe, train, and iron out the kinks.

STATUS INDICATORS TO RATE PATIENT'S STRENGTHS FOR IN-HOME-CARE

Taking into consideration Dad's life cycle, I assessed his personal strengths from a strength-based view of thinking using the status indicators I designed as an assessment tool. I used a scale of one to ten (0-3 poor; 4-7 average; 8-10 good) to determine his prognosis to remain in his home with in-home-care. I recommend using the following status indicators to guide your assessment of your AD patient. The following indicators will allow individualized planning, effective adjustments, and interventions when necessary:

STATUS INDICATORS

- Safety
- Stability
- Physical well-being
- Emotional well-being
- Prospects for permanence in the home
- Tracking and adjustment ability
- Medical

The safety status indicator for our dad is an "eight." All safety adjustments were made in his home equivalent to the child safety recommendations for obtaining a child care license. The only outstanding issue was the front stairs to his house that could become problematic if he fell

or could no longer walk. This would definitely jeopardize his ability to remain in his home.

The stability status indicator for our dad was a “ten.” He has always been considered a very strong, reliable, secure, well-grounded man. His life cycle confirms these characteristics. He had been married for 58 years; lived in the same home for approximately 50 years; a retired fireman after 25 years of service; a retired skycap after 30 years; and a United States army veteran.

The physical, medical, and emotional status indicators are rated a “ten.” There are no serious medical or emotional conditions other than the AD. The other medical issues such as high blood pressure and cholesterol are stabilized by medications and diet. He has chronic anemia, which is often considered a condition of aging.

The status indicator for the prospects for remaining in his home is good and is rated an “eight.” Because of the total reliance on 24-hour live-in-care in the home with independent caregivers, and the issue of the 16 front stairs to his home, it was downgraded from a ten.

The status indicator for monitoring, tracking and adjustment ability is rated a “nine.” This was the result of the daily logs which caregivers are required to do; almost daily unannounced visits and frequent telephone calls; and our efforts to encourage open communication with the caregivers.

Our dad’s overall score from the status indicators is a “**nine**,” which is good! Therefore, his personal prognosis for successful in-home-care looks favorable. We recommend that you use the sample prototype I provided as a guide for the assessment of your patient.

At this point, you are now armed with information about the life cycle of the patient that you may or may not have known before. As the old adage goes, “knowledge is power.” You are now becoming better prepared to assess the needs of your patient. For example, before my interview with our dad in 1994, ten years before the onset of AD, I never really knew about the major influences in his life in the sequence that he narrated and shared with me during the interview and how they impacted our family life. By now you also know about the stages of AD and the changes that may manifest or have already begun to be symptomatic. You also should have an idea of the patient’s strengths and their daily living activities (DLA). The next step is to take a good look at yourself, your family, and your relationship with each other and the perspective patient. Also consider your overall knowledge, skills, ability, temperament, and commitment to provide compassionate quality care to an AD patient.

FAMILY STRENGTHS ASSESSMENT

I established the same rating scale of zero to ten to determine the strength-based view of a family (0-3 poor; 4-7 average; 8-10 good). The foundation for this component is honesty about the past, current, and future relationship with you and the patient. It is based on integrity and trust in the ability and commitment to provide in-home quality care to the patient.

For example, I have a small immediate family, which could be problematic if there was little to no support within our family unit. Larger, stable families may be able to provide more support using a strength-based plan of care if they commit to the care of the patient – their time and many financial issues can be shared amongst more family members. My sister-in-law’s family of five siblings shared caring for their mother. They opted to keep her in her home and each committed to spending a night with her on a rotation basis. An In-Home-Support-Service worker provided care during the day. I also read about a family of seven who agreed to share the caregiving roles in their own unique way. The heavy, muscular brother did the heavy lifting, i.e., from bed

to chair or car. A couple took a night or weekend shift. One agreed to pick up the mother from a day care program. Then all the siblings agreed to contribute \$30-\$210 dollars a week to hire a family friend to provide care for a discounted hourly rate for all the other times. These are examples of a close family relationship and proof that "where there's a will there is a way."

Our family is small and the responsibility for providing care for Dad in his home falls on just the two of us, me and my brother. The following is an objective assessment of my family unit (me and my brother) as an example of this category:

FAMILY STRENGTHS ASSESSMENT CATEGORIES:

The categories of family strengths require an honest assessment as to whether your family is: close (8-10 good), casual 4-7 (average), or estranged (0-3 poor):

A close family relationship is loosely described as a mutually good relationship evidenced by frequent communication, whether physically, verbally, or even via written correspondence. There are basic elements of trust and integrity.

A casual family relationship lacks consistency. There may be little to no trust elements involved in the relationship, probably due to irregularity, unreliability, and because overall, the relationship just lacks heart. However, a casual relationship can become a close one if a need exists and there is commitment from the patient and the caregiver.

An estranged family relationship is generally riddled with discord, antagonism, and often hostility and resentment. The element of trust has been breached. It would take a great deal of work to turn an estranged relationship into a close one in order for the patient to feel secure about receiving quality care and confidence that the family member(s) is committed to providing compassionate care.

Some of the prevalent factors that could be problematic in family relationships when considering a caregiver role that should be assessed and discussed when considering quality care for an AD patient are:

- Drug and alcohol abuse problems
- Past history of a harmful or tumultuous relationship
- Mentally or emotionally unstable
- Inability to provide patient with consistent physical needs
- Has serious medical condition(s) of their own
- Lacks skills consistent with patient's PADCP and there is no secondary caregiver
- A criminal record
- In it for the money/just a job attitude

These factors, if unresolved, could have a negative impact on the trust factor, which is a key element in the family strengths category, especially when finances are involved. And finances inevitability are always involved! When these factors are not identified early on, the impact can be devastating later. Think about the countless elderly who have been victims of embezzlement by relatives and or caregivers, or worse, the mismanagement of care that can ultimately lead to their death.

After much deliberation, **under the category of family strengths, I rated my family a “ten”**. This was based on the fact that the three of us are a very close-knit family. In other words, “we’re all we’ve got.” My brother and I are equally committed and involved in keeping our father in his home for as long as it is humanely possible and in his best interest. In addition, our dad has communicated on numerous occasions that he trusts my brother and my decisions on his behalf before the AD progressed and robbed him of the ability to do so. The timing of trust is very important, especially as it pertains to finances. My brother and I both have *Durable Power of Attorney for Healthcare* on our father's behalf and are co-executors in his living trust. If you are primary caregivers or adult children, I recommend that you

have these discussions when the patient is lucid, and hopefully, prior to the diagnosis, just in case the patient is further along than suspected. Equally as important as a patient's plan for care, is the plan to pay for the care.

Under the category of the family's knowledge of AD, I rated me and my brother a "seven". In 2004, when Dad was initially diagnosed, we knew very little about the disease. We did not know that we needed to be prepared to actually witness the robbery and destruction of our dad's mind. AD is not simply a severe memory problem. AD destroys a patient's ability to understand, their awareness, their ability to comprehend and reason, their intelligence, and their ability to articulate. It's a brain disease that robs the victim of all the essential connectors that signal and inform the brain to function and how to function.

You need to know what you're getting into and what you're up against. Many family members believe that it is the moral and honorable thing to step up and become the sole care provider for their loved one. Big mistake! Unless you have acquired some experience or training in AD care, you are walking into a world unknown to you. It is almost imprudent because unknowingly we may do emotionally harmful things to the patient, which robs them more of their sense of well-being – remember the disparaging looks and statements that my brother and I were guilty of in the earlier stages of Dad's diagnosis that I pointed out and addressed earlier?

Under the category that the family is an expert on themselves, I rated my family an "eight." This is based on the fact that our father continually expressed a strong desire to remain in his home. My brother and I have our own homes. I am single, but my brother is married, with adult children and grandchildren at home. Dad did not want to live with either of us. And neither of us could live with him in his home on a permanent basis, and provide the 24-hour care and supervision that was necessary. In addition, both of us were employed at the time Dad was diagnosed. Our individual circumstances made it prohibitive for us to be the

in-home-caregiver. We do, however, live close to Dad, and are no more than five minutes away.

Still, I did give up my home and subsequently moved in with Dad for a six-month period. I was there to oversee the transition of our first live-in-caregiver. It was very difficult and challenging for me, and it gave me a glimpse into being the sole caregiver. During that time my brother and I concluded that in order to keep our dad in his home, we had to provide 24-hour care and supervision via a live-in-caregiver. Even though my brother and I disagree with each other on some issues, we agreed to respect each other's opinion and the right to disagree. Most importantly we decided that open communication is of utmost importance between us when it came to Dad. If we don't agree on something, we work together until we resolve the issue while also managing it.

Under the category of the family's ability to make well-informed decisions related to keeping our Dad safe with support, I rated my family an "eight." This is based on the fact that while my brother and I thought we were committed to keeping our father safe with support, we inadvertently hired some unscrupulous caregivers in the past due to financial circumstances combined with the urgent need to hire someone. We have also learned that we are not alone in this predicament. I have been diligent, even tenacious, about seeking information regarding AD and the resources available to us. We immediately made Dad's home safer for him by removing all area rugs to mitigate falls; purchasing monitors in the primary rooms in the house; placing night lights in his bedroom; and having lifeline service installed in the house.

As our knowledge and training increased, we were able to provide our dad with more emotional support, which was the basis for me to develop a PADCP prototype to help others as well. Built into this PADCP is the ability to track behavioral and cognitive changes and make adjustments as the AD patient progresses through the disease stages. However, we finally realized that the key to our father's safety is in hiring caregivers with verifiable

training and experience in providing 24-hour live-in-care from reliable sources. We are now more discerning in our recruitment, interviewing, and hiring techniques.

Under the category of the family's desire to treat our father with dignity and respect, I rate my family a "ten." This is based on our Christian belief and the commandment "To honor thy father and thy mother." Dad has been grounded in his faith all of our lives and has been our example. In addition, our father has always been an excellent parent, provider, friend, and mentor. We, in turn, have the utmost respect for him, and believe he deserves the best care that we can provide for him.

Conclusively, our dad's daily living activities were favorable and confirmed his personal strengths, and supported the assessment that he could remain in his home. All of the family strengths indicators for me and my brother are rated good, indicating that we are appropriate primary caregivers for providing care in Dad's home. Now there is one missing link. Can you guess what it is? The last component may be optional for some primary caregivers, but for me and my brother, it was absolutely mandatory.

We must have good quality caregivers to assist us in order for our dad to remain in his home. Therefore, I designed an In-Home-Caregiver Profile for AD patients as a tool for the In-Home-Caregiver Assessment for hiring quality in-home-caregivers (a.k.a. providers), in-home-support-service workers and independent contractors. Often, these terms are used interchangeably. *Stolen* centers on all caregivers paid for their services. The primary area of vulnerability for keeping Dad in his home was and continues to be our ability to hire quality, affordable caregivers. This had been our most insurmountable challenge, which gave me the *caregiver blues*.

CHAPTER 7

CAREGIVER WITH A CALLING



EVERYONE IS A CAREGIVER!

We all have a purpose in life. In fact, I believe that we were all created to contribute some type of service on this planet called Earth. It is a blessing for all concerned when a person knows their purpose or mission in life and expresses it through the service of others. When we are aware of our talents and gifts, we should feel honored to share them by either doing volunteer work or if so fortunate, through one's career. In fact while listening to a radio talk program one day, I heard caregiving referred to as a ministry. That was a defining moment for me. I definitely wanted a person who feels as though they have a calling to provide such a personal and intimate service as caregiving to our father. A caregiver who just wants a job providing the basic care of feeding, clothing, cleaning, safety, and other errands to an AD patient for pay is only providing minimal care. They lack compassion and often times, many just don't seem to have heart!

No, I am not in denial. I realize that being a sole caregiver for an AD patient can be very stressful. Being a paid caregiver is equally as stressful, if not more, because it is very isolating, especially if you are providing live-in services. To provide quality care to an AD patient, caregivers have to relate to "their" world. And they live in the world of the "now" because the memory of something that was either said

or done three minutes ago has either passed or is fading in the mind of the AD patient; it is a different reality from that of the caregiver. The million-dollar question for me and my brother became, "Does quality care for our AD patient require a special caregiver or simply a caregiver who has chosen caregiving as their special calling?"

Let me try to distinguish between the two ideas. I have observed that a person who calls him or herself a caregiver because it is an employment opportunity (job) is very different from a person who is aware of their special gift. They share the gift by giving of themselves to provide caregiving for others. The latter is motivated by a personal desire to help others. They take an interest in their work, seek information about what their responsibilities are, and most importantly, they want to be a caregiver that shares and imparts their gift of compassion, empathy and nurturing spirit. They establish a relationship with their patients and provide care with a joyful spirit.

CAREGIVING REDEFINED

Trying to find and hire the best caregiver we can afford for Dad has been an ever-evolving process. What I've finally realized after eight years into this journey is that the term *caregiver* is very generic and subjective, almost similar to the term quality health care. Former First Lady Rosalyn Carter has started an institute for caregiving referred to as Rosalyn Carter Institute (RCI) to address what she and many perceive to be a caregiver crisis. It was very illuminating to read Mrs. Carter's statement: "There are four people in the world: those who have been caregivers, those who are caregivers, those who will be caregivers, and those who will need caregivers." Well doesn't that sum things up? Which category do you fall in?

To validate Mrs. Carter's statement, I realized that most of my friends and associates have been caregivers, currently are caregivers, are aware of becoming caregivers in the near future, and some are considering the need for one for themselves in the not too distant future. It is obvious that, with only a few exceptions, the call to be a caregiver at some point is inescapable. Further research revealed

that although there are some exceptions, caregivers today are in their 50's and 60's and are the children of the elderly.

The prevailing opinion appears to be that never before have so many adult children seen their parents become so dependent on them for care. And closely related, never before have so many working adults been faced with the conflicting responsibilities of caregiving and careers. The elderly, our parents, are living relatively healthy lives well into their eighties, nineties, and beyond. Ironically, their dependency occurs at these later stages and is due to chronic illnesses. This is the challenge that we are facing in the 21st Century with our parents and loved ones. This is exactly the challenge my brother and I are facing with our dad. There is an increasing demand to provide in-home-care for chronic illnesses of the elderly and AD is definitely a chronic illness. By definition, chronic illnesses are not curable and are usually long lasting with specific health consequences. They don't require hospitalization or medical care because they are often stabilized with medications and/or medical equipment. By 2030, nearly 150 million Americans are projected to have chronic conditions, and 42 million of them will be limited in their daily activities or dependent on assistance. Among them, it is estimated approximately 12 million will be unable to live without involving caregivers in their lives.

In my opinion, although AD is considered a chronic illness requiring custodial care, it requires specific or specialized training. Caregiving for an AD patient typically begins with little chores such as grocery shopping, driving, cooking, housekeeping and banking; then develops into personal care chores such as bathing, feeding, assistance with walking, incontinence and insomnia issues, and includes a host of functional, behavioral and cognitive challenges. begin
go on

It was a light bulb moment! If most of us are or have been caregivers-that is why in our search for caregivers for our dad-almost everyone has said they were a caregiver. A caregiver can be a spouse, son, daughter, any relative, neighbor, friend, and the list can go on and on. Therefore, I finally came to terms with the

fact that we really needed to be more specific than just requesting a caregiver. In the earlier days, we were getting exactly what we were asking for, *a caregiver!* We needed caregivers with a calling and a particular character and personality profile and specific training and/or experience with AD patients. We really needed a caregiver with specific skills, even though Dad didn't look sick and was very functional. Yet there were behavior and cognitive issues Dad exhibited that popped up that the past caregivers were unable to address or handle adequately because they were generic caregivers – untrained and ill-prepared in the area of AD.

★ Perhaps it was unfair for us to expect them to perform at a higher level. On the other hand, our expectancy for their performance was based on their representation in the interview that they had experience with AD patients. Today we request a Certified Home Health Aide or a Certified Nurse Assistant with experience in caring for AD patients, and we look for certain qualities in the person which are descriptive of a vocational caregiver.

THE CALLING

♥ ★ What is that? Essentially, *The Calling* to me, is a vocational caregiver with a passion for what they do. They have decided to make caregiving a career. It is their life's work, also recognized as a *calling*. In the beginning of our search for a caregiver for Dad, we knew that we were looking for an honest individual with integrity, a good personality, a good sense of humor, and the ability to articulate him or herself, along with being able to provide Dad with his basic needs. It became evident that in order for our dad to experience the best quality of life that we could provide, I had to revisit and refine our criterion and become more specific about the qualities and characteristics required of a caregiver that would be beneficial to our dad's sense of well-being and his best care. At the risk of sounding a little esoteric, I came up with the concept that AD patients need a caregiver with a personal quality I refer to as a "joyful spirit." This is a person who has a sense of personal integrity and an outstanding personality who celebrates their life and will celebrate the patient's

life. When working with a patient, they are in relationship with ^{pt} them. She or he also has the following qualities and characteristics listed in my Caregiver Profile for AD Patients:

Caregiver Profile for Alzheimer's Patients

- Joyful spirit
- Self-respect (because without it they can't respect the patient)
- Knowledgeable about the dynamics of AD
- Treats patients with dignity and respect
- Encourages independence
- Has a good sense of humor
- Espouses hope
- Is creative and thinks out of the box
- Takes pride in their work
- Is receptive to suggestions and training (+ teachable)
- Is mentally and emotionally stable
- Has a strong sense of work and personal ethics
- Physically healthy and drug free
- Creates a stimulating environment
- Advocates on behalf of the patient



Many AD patients reach a point where they can't decipher written words, or understand what they are reading or looking at.

Ultimately many forget how to read. Therefore certain situations requiring that skill can cause a further sense of personal loss. Case in point: Restaurants can be very noisy and distracting places. The menus and ordering protocols can be difficult to understand for many of us not afflicted with AD. I mean it's not uncommon for us to ask the waiter questions about what's on the menu for clarity.

To avoid or alleviate the frustration and anxiety that could occur for an AD patient in a restaurant, I suggest discretely ordering for them. When the waitress places the menu in front of them, the caregiver should pick up the menu and review it with the AD patient. Rather than asking them, do you want chicken, turkey, steak or fish, you might suggest a short list of choices: "Dad, would you like fish or chicken?" We often fail to be in "their" world when we add, "the veggies sound good too: broccoli, spinach, asparagus, and there's mixed vegetables, and you even get soup or salad."

This is TMI (Too Much Information) for an AD patient to absorb. Too many choices are confusing to them. It is better to ask the AD patient if she/he wants chicken or fish. That's it! After their response, then ask if they want soup or salad. It is very important to keep the AD patient in the loop, and feeling like they are participating in making the decisions. I'd like to share a suggestion that I read about that works well for us in restaurants.

If I have a preference for Dad, I'll say that item last. For example, if I think fish is a better choice for him that day, I would say to him, "Would you like chicken or fish?" Studies have shown that Dad would most likely say fish because it's the last word he heard. Therefore, it is the last word remembered. I must say they were right because this suggestion works every time. I have noticed that Dad seems very pleased about the decisions he makes, and I am pleased that we continue to make the effort to keep him in the loop.

There are numerous instances when a caregiver's advocacy is beneficial to the overall well-being of the AD patient. It's the attention to details that can make a difference. I don't know how

often I've had to pull a nurse or a doctor aside to inform them of my father's AD condition. Even though he appears confused and unable to answer their questions, they persisted in asking him. In the Middle to Late Stages, Dad would often forget his name, age, and date of birth. You could see his embarrassment, which I would try to minimize by making a joke, like, "Dad, you've been here so long it's easy to forget." Humor is one of the best ways to clear the air. To laugh at one's self is a true gift. Try to find humor whenever and wherever possible.

Advocacy is definitely necessary when hospital staff recommend convalescent homes to primary caregivers and when convalescent home staffers recommend long-term care in their facilities for custodial purposes to unsuspecting primary caregivers. Oftentimes, the AD patient can be cared for in his or her own home with the assistance of an in-home-caregiver. That's not to say it's an easy task, as you've probably noted from reading the previous pages. However, if you are contemplating out-of-home care, in deference to the patient, always assess the pros and cons of having the patient remain in their home or your home first. I just want to reiterate that I believe my Assessment Tools will help you make an informed decision.

THE INTERVIEWING PROCESS

I recommend that you look for the qualities and characteristics listed in our AD Caregiver Profile as well as decipher the knowledge, skills, experience, training, and abilities using our "Interview Questions Tool." The following is an example of how you integrate the two: we interviewed a caregiver whom we asked what some of his experiences with AD patients were. He answered by telling us about a previous patient who became very annoyed and anxious in the room with his relatives at a party. He realized that no one was talking or interacting with the patient, so he went over and engaged the patient himself. Even though the patient's conversation was riddled with confusion, the interviewee said, "You just flow with it." These statements confirmed my feelings about Dad, whom I had observed would become agitated and even angry when people were around

him and ignored him in his own home. Further, this caregiver stated that many AD patients become upset and shut down, or some become passively aggressive and simply are unresponsive and uncooperative the remainder of that day as payback for being ignored.

The experience he shared and his awareness of the AD patient's passive aggressive behavior confirmed for me that the caregiver did have experience working with AD patients and had handled the situation well. It was actually a defining moment for me about his ability to care for Dad. He appeared insightful about how some AD patients may think. He skillfully applied his knowledge in this situation to resolve what could have become a serious behavior issue at the party.

If you are wondering if we hired this individual, we did! He had come highly recommended through a referral, mind you. There's really no substitute for good references. The operative word again is *good*. He accepted the position and was scheduled to begin work the following week. When I called to confirm the time he was to report to work, he informed me that he decided not to take the position. He was offered another opportunity that paid more money.

Please note the following: First, I called him. I have no idea when or if he had intended to call and inform us about his change of plans. Second, he expressed no remorse for the inconvenience he caused. Consequently, we were left hanging because we had terminated the services of the previous caregiver expecting the new hire to replace her. I could not believe this was the same person we had interviewed who came across as sensitive, considerate, and empathetic. What's the moral here? I really don't know. This individual was highly recommended to us. I think it may be the nature of the job, but you still must continue to do your due diligence and move on. Closely related, do not assume that because a caregiver is referred to you, comes from an agency, belongs to an in-home-care union, has a Certified Nursing Assistant license, or is a Certified Home Health Aide, that they know how to provide the type of empathetic care enumerated in this book. They must be orientated to your PADCP.

This is why it has become mandatory that we hire a caregiver who is teachable or coachable.

If you decide to locate and hire your own caregivers as we have, I suggest that you have another person join you in the interview process. When I first started interviewing caregivers about eight years ago, I did it solo. Now my brother and I conduct the interview together. When I'm asking questions, he's observing the interviewee's body language and vice versa. After the interview we share our observations and make a decision whether to pursue this caregiver further by checking job and personal references, etcetera.



INTERVIEW QUESTIONS TOOL

The following is our Interview Questions Tool (IQT), a sample of important interviewing questions for the care of AD patients:

1. How would you describe yourself, your personality, and your job history?
2. Have you worked with AD patients before and where?
3. Have you ever been a live-in (24-hour) caregiver?
4. Ask as a caregiver, have you ever had a job involving a 12-hour or 24-hour shift change?
5. Will you provide or require a live-scan as a condition for employment?
6. Do you smoke cigarettes?
7. Do you have a car? If so, do you have a valid driver's license and auto insurance?
8. What type of meals do you prepare for yourself? Where do you shop? Do you enjoy cooking?
9. Do you watch TV a lot? What are your favorite programs?
10. Do you know what the term "sundowning" means? Explain in your words.
11. How would you handle sexual statements or advancements from an AD patient?
12. Ask the caregiver if they have ever worked with a patient of the opposite sex. If so, ask if they were comfortable with activities such as dressing, bathing, and incontinence.
13. Ask if they have a checking account or a means of cashing personal checks.
14. Do you have any hospital scrubs? Do you mind wearing them on the job?
15. Do you have a recent TB clearance report? Have you had a CPR class and do you have a current CPR certification?
16. If a caregiver's cultural background is unclear to you, ask them about it.

If you are concerned about their ability to understand and follow your Personal Alzheimer's Disease Care Plan (Do not ask about their race or ethnicity because this is illegal)

RATIONALE FOR THE INTERVIEW QUESTIONS

- 1. Asking the interviewee to describe themselves and their employment history is important in order to determine whether their verbal description of themselves matches their real persona and background.**

I'm a bit embarrassed to admit that my brother and I have actually hired a few caregivers who visually appeared depressed. Due to the sense of urgency to hire, we consciously or unconsciously chose to ignore their signs of depression that were revealed to be true later after the caregiver had been hired. This is a big mistake. You should pay attention to your intuition. If something doesn't feel right or statements are conflicting, *don't ignore it – explore it!* Caregivers are trying to size you up the same way you should be seeking to size them up. They try to say and tell you what you want to hear. You want to ask appropriate questions to get answers about the interviewee that you are interested in knowing. You may ask them: Do you have a sense of humor? Are you a serious person? Are you patient? Are you out-going? What do you enjoy doing? Their answers will reveal a lot more about them than simply the words themselves. For example, choice of words, body language, expressions speak volumes.

Many AD patients need to be around upbeat and positive people, particularly in the Early and Middle Stages of AD when many are still communicative and alert. You need a communicative person who will help the patient keep their verbal skills for as long as possible. You need a caregiver who interacts with the patient as a person rather than an object that they feed, clean, prop in front of the television, bathe, and put to bed.

A caregiver with a sense of humor possesses an excellent personality characteristic, especially for an AD patient. It is such a wonderful

feeling to hear your AD patient laughing heartily. It really warms your heart and laughter is known scientifically to be healthy. Equally important is to try to determine if the caregiver has initiative. You want someone who is creative and will invite and engage the patient in tasks and activities they can continue to perform as well as try to find alternative ways to compensate for failing skills.

→ Some medical background should be required in order to care for an AD patient properly. A Certified Nurse Assistant (CNA) or a Home Health Aide (HHA) is sufficient when the patient doesn't have serious medical problems. But you definitely want a caregiver who can take vital signs, and their relevant training for this job should be in caring for AD patients. Many independent caregivers are also registered with home health registries and agencies, and have current live-scans, and have active certifications such as CPR and TB clearances. Verification of this information can take a load off of you.

2. **Determining whether the interviewee has provided care for an AD patient is a very important factor.**

When asked this question many caregivers will say yes! However, it is crucial to distinguish actual pay for services as an in-home-care provider from those who have simply helped with the care of relatives and friends, reportedly with AD. Many of these interviewees refer to their family members as having memory problems with no recognition or training in dealing with the cognitive and behavioral changes due to the disease. You need to inquire about their understanding of AD.

★

The disease presents such a roller coaster of symptoms that I have found that a caregiver with AD training can calm the primary caregiver down and manage the patient. As mentioned earlier, sometimes symptoms that mimic other serious illnesses will surface and you will want to call 911 or run to ER, but in actuality, the patient is just having a bad day. A CNA or HHA who is trained and knowledgeable of AD specific behavior will take the patient's vital signs, check for dehydration, and monitor for a couple of hours before going into a crisis mode.

Many have not even read a book(s) on AD, which could possibly substitute for training in the area. Such self-initiative says volumes about the caregiver. If the interviewee has provided professional caregiving services, ask for the names and phone numbers and call these references during the interview. This is crucial because if you wait and call the references days after the interview, some unscrupulous caregivers give their friends as references who confirm whatever is necessary for them to be considered for the job.

3. Hiring a live-in position can be tricky. Some of the less experienced caregivers may claim to have live-in experience.

Ask the interviewee to describe their live-in experience. Further exploration will reveal that a 12-hour shift is often considered a live-in position i.e. 8 a.m. to 8 p.m. Technically, a caregiver does not, or should I say, should not, sleep on a shift. However, many primary caregivers similar to my brother and me require a 24-hour shift – a live-in position compensated on a flat rate basis rather than an hourly basis. Their lodging, food, and all of their physical needs are included in the flat rate. A 24-hour shift can be very feasible when patients are in the Early to Middle stages and relatively healthy, and if the caregiver is experienced and therefore able to manage the patient's behaviors. Always keep in the forefront of your mind that a live-in position can be very isolating for the caregiver, and most likely you will be hiring a total stranger who will be in total control in the home. The job requires a person who is flexible, with integrity, ingenuity, creativity, and organizational skills because they will be overseeing and supervising your loved one and running their household. Many registries and in-home care agencies recommend two 12-hour shifts for a 24-hour live-in position based on hourly compensation. However, that was prohibitive for us. We simply couldn't afford it! And if we could, I had reservations about agencies because often they send different people daily or weekly, and weekend care can be challenging, even for these agencies. With agencies, you may be more vulnerable to more strangers in and out of the patient's home.

4. Whether you have a two 12-hour shift coverage or a 24-hour day coverage with one caregiver, inevitably there is shift change.

There are certain protocols when the shift changes. For example, some tasks are to always leave the patient clean and fed; laundry all items soiled during your shift; inform the in-coming caregiver on the current status of the patient. Many caregivers registered with agencies are informed about these rules of conduct and are trained accordingly. Unfortunately, many independent caregivers are unaware of a lot of these rules of conduct as well as other, such as wearing scrubs to work, not smoking in the house, discreetness in using their cell phone, punctuality, telephone etiquette, and being receptive to primary caregivers' requests. Ultimately, cooperation, communication, and reliability are essential in executing seamless shift changes. Always try to acquire and maintain a list of backup caregivers in case of emergencies when there is a no-show due to illness or family emergency. This is more easily said than to actually do!

5. **Most agencies require their employees to “live-scan” annually.**

If you're hiring an independent caregiver, you're responsible for “live-scanning” and obtaining recent medical history. You can pay for it or transfer the expense on to the caregiver. But you should get it! I hate to admit it, but my brother and I once hired a lady who had just been released from jail, unbeknownst to us or the person who had referred her. She interviewed very well – saying all the right things, such as she loved working with older people, and caregiving was a blessing to her and the patient. Her reference checked out, and we were desperate again, so we hired her without doing a live-scan or criminal record check.

The day before she was to report to work, she was arrested for a probation violation, which was later discovered via the Internet by my brother when she didn't show up. This was a third strike for her, and she was subsequently sent off to prison. DMV is also a source for criminal record checks, but the caregiver must request it. So definitely get vital personal information such as birthday, driver's license, and social security number during the interview.

(Caveat: Months later after she had been released, she actually called with a made-up story about where she had been and wanted

to know if the position was still available. People are amazing! Be watchful. Do your due diligence.)

6. It is best to hire a caregiver who is a non-smoker for the care of an AD patient, and probably any other patient.

Half of the caregivers we hired since 2006 have smoked cigarettes. Our only request is not to smoke in the house or in the car when our father is present. So the question becomes when do they smoke and who is watching the patient? We've requested that they smoke on the patio where they can see Dad through the sliding glass door.

7. Many caregivers don't have cars.

It may not be an issue for you, but the caregiver requirement to own a car is crucial for us. Small errands such as picking up medications, going to the cleaners, and grocery shopping, allowed Dad to get out of the house. We have observed that when Dad is told he's going somewhere, almost anywhere, it seems to give him a reason to get up, shower, and get dressed. It gives him a purpose for that day. Quite frankly, I believe it allows an outlet for the caregiver as well. They spend many hours one on one with an elderly person whose interest and temperament is different than their own. If you have a second car, allow them to drive it for errands during their shift. When they have a car, ask to see their driver's license and proof of car insurance and definitely record it.

8. Questions about grocery purchases, meal preparation, and serving are very important.

A healthy, balanced diet is very important for AD patients. Healthy can be very subjective. By asking the caregiver what are their favorite foods, and what kind of meals they prepare daily for themselves, you get an idea of what they will be preparing for your patient. You must advise caregivers about the type of food and meals the AD patient enjoys.

Most people who enjoy cooking also prepare tasty meals. If a caregiver reports that they don't do a lot of cooking, eat out a lot, or don't enjoy cooking, that could be a sign of what is to come for your patient. You want a caregiver that is conscious of nutritious and healthy types of food and meal preparation. Caregivers who have training and experience



are aware of the importance of keeping a patient hydrated; eating with the patient; preparing finger foods; providing healthy snacks; serving small portions; cutting up the food; and keeping a minimal amount of utilities on the table. All of these rather simple techniques are either easier or better for the patient.

9. Asking a caregiver if they watch TV a great deal gives you an indication whether the TV will be running all day and night.

If so, expect an increase in your utility bill. The jury is still out on whether sitting an AD patient in front of the TV all day is beneficial or not for the patient. Many sources consider the TV "company" for the patient. However, often times I have observed that the television appears to be more company for the caregiver than the patient. Many AD patients literally appear to zone out or simply fall asleep when positioned in front of the TV because they can't follow the story line. The drawback is that TV is not interactive. It is passive and doesn't require participation from the AD patient. At some point, they will need assistance from the caregiver to explain literally what is going on in the program. For example, at some point, Dad could no longer distinguish between commercials and the program or movie.

10. Problematic behavior that occurs late in the afternoon or early evening with AD patients is often referred to as the sundown syndrome or "sundowning."

Actually, many clinicians have determined that this syndrome often occurs between three and eight o'clock in the evening. The symptoms are generally described as a time when overall behavior becomes worse and activities such as wandering and agitation increase. There's not a definitive reason why sundowning occurs, but many sources believe that it's associated with lower light levels later in the day, in conjunction with patient fatigue, lessened stimulation, and lower tolerance for stress. The key here is awareness! You want a caregiver who is aware of the sundown syndrome and will try to plan accordingly and adjust. For example, try not to schedule important appointments in the late afternoon like medical appointments. Turn on the lights and

close the drapes when the sun starts going down and it begins to get dark. Not all, but a significant number of AD patients experience sundowning.

11. Many AD patients make sexual advancements or make inappropriate sexual statements.

A trained caregiver cannot take these incidents personally. In fact, most from our father are harmless statements. Asking a caregiver how they would handle a sexual request such as an AD patient asking for a kiss is very revealing. Even more revealing is their reaction to the question. If they look repulsed by the question, that's probably a sign they don't know about the nature of the disease, or have not been trained on how to handle these types of situations. ★

→ To confirm or verify that they are not experienced in this area, ask if they are familiar with the term or process of "redirecting." An example, of redirecting is saying, "I'm not feeling well today, would you like some cake and ice cream?" Basically, you turn their attention away from the subject of a kiss. And guess what, they'll probably forget they even asked the question or made the statement 15 minutes later. You definitely don't want a caregiver who becomes fearful and chastises or shames the patient.

12. Working with patients of the opposite sex can be challenging.

You want a trained caregiver who is comfortable with activities such as showering or bathing, and dressing the patient. These intimate activities must be handled confidently and with respect and dignity. (You want a caregiver who has ingenuity, creativity, and a sense of humor helps.) For example, incontinence is inevitable with an AD patient. Ask the interviewee how he or she deals with this issue, and really observe their body language. Expressions of embarrassment, frustration, and disgust are some examples of how a caregiver's reaction can take away an AD patient's dignity more than the disease itself! Our father appears to really do well with women caregivers. The primary caregiver may want to ask the AD patient if they prefer working with a man or woman. I have a

feeling many women may prefer the same sex caregiver more than men. Our father definitely appears to prefer female caregivers!

13. Surprisingly, many direct pay or independent caregivers don't have checking accounts.

Paying with cash can be a problem. Withdrawing large sums of money from an ATM weekly can be dangerous for the primary caregiver. In addition, most primary caregivers want a record of this expense. Unfortunately, primary caregivers must be careful of cash requests from independent caregivers, who may be receiving unemployment benefits or disability payments, which could possibly be incriminating. Do not look at this as an opportunity to pay less because they are requesting cash. You will get what you pay for. A good caregiver is worth their price in gold. And remember that ignorance is *not* bliss!

14. Most agencies instruct their employees to wear scrubs to work.

Scrubs are the hospital uniforms worn by nurses in hospitals and convalescent homes. Some agencies even instruct their caregivers to wear scrubs to an interview for a new patient. I prefer for scrubs to be worn when caring for our dad because it communicates a more professional persona. It also eliminates inappropriate dress choices. I think this is extremely important when a female caregiver is providing 24-hour care with a male patient. Tight pants and skimpy tops may be even more enticing to an AD patient, who may already be less (sexually) inhibited due to the disease.

On the other hand, our caregivers have the option of wearing scrubs to outings such as church, restaurants, and other specific places. On these occasions, caregivers can wear whatever they feel comfortable in as long as it is appropriate. In support of choosing scrubs, I have observed that when caregivers wear their scrubs when they take Dad out, it communicates a professional relationship, which many deserve. In fact, I have often observed that people who take notice approach them and request referrals because of their demeanor. Conversely, I have also noticed that caregivers who don't want to take Dad out and don't want to wear

scrubs in public, and don't want to be seen in public, have ulterior motives, i.e. they are receiving disability or unemployment benefits or have insurance claims.

15. Agencies require a TB Clearance and current CPR certifications.

You are on your own if you hire an independent caregiver. In the interview, many caregivers will tell you that they are healthy, but it is important that you verify this information by requesting copies of their medical status. Either the caregiver must sign a release of information for you to access their health record; or the caregiver can request the records themselves and bring you a copy. Obtaining health information on the caregiver is challenging because of the HIPPA laws involving confidentiality. Clearly, you need a relatively healthy caregiver. I also suggest that a TB test be required since TB is contagious. Home healthcare agencies and registries definitely require it. If you hire a CNA or HHA also registered with an agency or registry, they should have a current verification of a TB Clearance and a current CPR Certification, of which you should get a copy.



AD eventually compromises a patient's immune system and many vital organs begin to break down. For example, most doctors consider our dad very strong, healthy, and in very stable condition. Yet due to his age, he has chronic anemia; high blood pressure; a history with a gout and prostate episode; and he takes medication for his heart. I did not want to hire someone whose health could compromise Dad's health. But guess what? We did! My brother and I hired a caregiver who had hepatitis, which she didn't disclose of course, during her interview. That's why you must do your own due diligence when hiring independent caregivers.

16. It is important for caregivers to be culturally sensitive.

There are many diverse ethnicities and cultures in the United States. Our dad lives in Los Angeles, California. When interviewing a person from another culture to provide care for an AD patient, I

think it is important to inquire whether AD is prevalent or recognized in their country and how it is managed. We hired a weekend caregiver from another country. She informed me there were no nursing homes or convalescent homes there. Older people were simply taken care of in their home. Actually this is the case in many cultures. I was shocked when we requested her to do little things to accommodate Dad that she dismissed as unnecessary. For example, he complained that cold water was uncomfortable for him when he washed his hands. We asked her to temper the water first. Also, her tone of voice seemed a bit bristly to me. I'd listen to her speak to Dad and she would tell Dad to do things in a tone that sounded like an order. Dad does not respond well to orders. Consequently, it would take her a couple of hours to get him into the shower. He was very uncooperative with her, probably because he perceived her as impatient and not very compassionate. We had a similar problem with another lady from another culture. Often caregivers from other cultures have different food preferences. I believe that caregivers should prepare the foods requested by primary caregivers or recommended by doctors for the AD patient. They are invited to eat the food that they prepare for our dad. The caregiver, on the other hand, can purchase and prepare what they desire for themselves. Should we pay for a caregiver's food if it is different from what we purchase? The jury is still out on that one. Right now, we don't!

Not everyone is cut out or able to do the work of an in-home-caregiver with AD patients. However, many people think they can at your expense. The caregiver profile that I developed is the result of numerous interactions and interviews with caregivers on our father's behalf. I have actually observed that the caregiver qualities and characteristics listed have a positive impact on the performance of a patient's daily living activities and their behaviors. They reduce undue stress that would otherwise impact the patient and caregiver negatively. I can testify that the caregiver qualities and characteristics recommended in our Caregiver Profile for AD Patients promote positive emotions, optimize functioning, and maximize successes. It is of the utmost importance to observe and assess the AD patient's mood/behavior around the

caregiver. Remember that their nonverbal communication tells a great deal, so pay attention. If I had not paid attention to Dad putting his cap on for what seemed no reason, I would not have known that his putting on his hat was one of many signals of his readiness to get out and go.

The more I continue to observe our dad in his home environment, the more I am convinced that placing him in a convalescent home would only have been convenient for my brother and me. In a convalescent home, Dad would have probably become more confused, depressed, and alienated. This is based on observing his behavior during the brief times he spent in a couple of them. Even though he doesn't realize that he's in his own home most of the time, I sense in him a comfort level that he experiences it as *being home*. In a convalescent home, he wouldn't be taken for daily drives. He wouldn't have daily baths or showers. Because Dad requires assistance walking, they would probably give him a urinal in bed that would be difficult to use because he wouldn't understand how to use it. The other possibility is that he would be wet from a urine-saturated diaper or sheet because of lack of adequate staff to assist him to the bathroom and clean him up when necessary. And need I mention what this can lead to physically? Should we mention the potential for sores and infections and possibly death?

Because our father can be stubborn, he probably would fall trying to use the bathroom on his own, especially at night when supervision is scarce. In fact, we did receive an incident report at one of the facilities reporting that Dad fell in the early morning, we never learned the resulting circumstances. However, keeping Dad in his home only works with good caregivers. To reiterate again, finding good quality caregivers to live-in and provide professional care for your AD patient is no walk in the park. My brother and I have adjusted our attitudes, and we are working from a strength-based concept, with a well-defined PADCP. In other words, we have a plan of care that is personalized to meet Dad's unique individual needs in the safe, loving, and nurturing environment of his own home. Lastly and equally important, and perhaps most significant, is finding and hiring the best caregivers we can afford to be a part of our team.

Good live-in-caregivers are really an extension of us. We know they're out there!

One day I was having an attack of the *caregiver blues* when I had an epiphany! I had been disillusioned too long. I knew that stopping short and falling into the trap of believing that "there are no good affordable caregivers" would not resolve the issue. We were determined to provide Dad with the best quality of life we could afford and to which he was accustomed. I finally got myself together and decided to overcome my sense of helplessness with a sense of empowerment.

Subsequently, I came up with the concept of caregiving and creative salary negotiations. In the 21st Century, the whole field of healthcare is growing and evolving. Universal healthcare has finally gotten its foot in the door in the United States, and President Barack Obama's administration continues to struggle to raise the consciousness of the general public about healthcare for all. In fact, his administration has even increased the budget on AD research because of the alarming, projected impact of AD in the next 20 years on healthcare.

AD is projected to reach epidemic proportions in the next 10 years. It is estimated that at the age of 65, one in ten persons will have some form of dementia or memory loss. That figure jumps to one in two persons at the age of 85. Statistics show that women have Alzheimer's more than men. By the year 2050, an estimated 16 million people will have this disease, which lasts from three to 20 years. This will attract an influx of individuals into the field of caregiving – many for the right reason and some for the wrong reason – simply a job! I believe that now is the time to raise the bar in caregiving, especially as it relates to in-home-care and independent contractors.

WHAT'S TOO MUCH OR TOO LITTLE TO PAY?

The same radio talk show that I mentioned earlier primarily gave a voice to paid caregivers who were In-Home-Support Service workers

(IHSS). The callers' primary complaints were their desire for higher wages. They reportedly received \$9 or \$10 an hour. As I listened I thought, okay, it is a demanding job. However, there are some caregivers who act as glorified babysitters, merely going to work to sit with their AD client and not to interact with them on a personal level. In fact, many treat the AD patient more like an object than a human being. They put the patient in a Depends diaper, sit food in front of the patient, and go on their merry way to indulge in their MP3 players/iPods, cell phone conversations, texting or soaps. This sort of business-as-usual is unacceptable behavior.

If you're demanding higher wages, then it should be because you deserve it. Your work productivity, responsibilities, and tasks must justify the demand for increased pay. For this reason I suggest that in-home-caregivers pursue specialized training for the care and treatment of AD patients and perform accordingly. Self-initiation goes a long way. And if a caregiver is good, the accolades and recommendations will follow them. Their complaints about salary reminded me of the complaints I had heard from some of the caregivers we hired. Their comments only fueled my interest in advocating on behalf of the defenseless AD stricken population. We wanted to be fair, but a flat rate of \$100 a day for a 24-hour live-in-caregiver is what we had to pay in the beginning. That averaged from \$3,000-\$3,200 a month, plus about \$1,000-\$1,200 a month for utilities and groceries. In 2006, our dad's net income a month was approximately \$4,200, which is not too shabby for a retired 90 year old. Yet, often his net income did not cover the expenses. The following are expenditures we failed to factor in as novices at providing 24-hour caregiving services in the home:

UNACCOUNTED FOR EXPENDITURES

- Insurance for caregivers often referred to as in-service insurance.
- House cleaning service (caregivers only do light cleaning).
- Purchasing Depends for daily use.
- Purchasing Ensure or Boost for daily use.
- Increased grocery bills to accommodate the caregiver's culinary requests and taste.

- Increased utility bills due to use of washing machine and dryer, fans, and showers.
- Time-and-a-half for work on holidays.
- Loss due to breakage.
- Increased household cleaning items, i.e., plastic gloves, various detergents for cleaning and keeping the house sanitary due to incontinence issues.
- Other unexpected purchases.

Ironically, you are not impacted by most of the items above if the patient is placed in a facility. But if these items and incidentals are not factored into the caregiving budget for your patient living at home, it can possibly create a hardship on those who are not financially prepared. I haven't even mentioned depreciation and replacement of items, home repair, and overall home maintenance. Our father was a blue-collar worker, a fireman with the City of Los Angeles. He receives a good pension, social security benefits, and has excellent healthcare benefits. His house is paid for and he has no debt. He was living rather comfortably, enjoying his life as a retiree. Life was good!

The catastrophic illness of AD has forced us to use all of his net income to try to provide quality 24-hour care in his home. Eighty-percent of his income is used to pay for caregiving fees and services, which most caregivers still claim are inadequate for their lifestyle.

On the other hand, I do empathize with caregivers who must also make a living, because many have families and if they are not content with their salary, it will surely reflect in their care for our dad. I pondered, "How could primary caregivers and paid caregivers empower themselves in this challenge to provide quality care in the home?"

This call for empowerment was the incentive that inspired my concept for creative caregiving and salary negotiations. A limited budget requires you to think more about available resources (services, skills) and differently about money. Primary caregivers, similar to us, could

offer paid caregivers incentives that have financial equivalents valuable to them for accepting the job. The following are some examples:

CREATIVE CAREGIVING INCENTIVES

- If they don't have a car, give them access to the family car for your errands and their reasonable ones. Or if you have a second car, then allow it to be used by the caregiver. This would probably entail paying for their insurance or adding them to your car insurance.
- Assist paid caregivers with additional income in your home (heavy house cleaning chores, sewing, and babysitting if there are other children in the home).
- Exchange services by bartering.
- Allow dual care of another patient in your home, which would generate more income for in-home-caregivers.
- If cooking is another skill, for example, allow the paid caregiver to prepare meals in your home to sell to the public.
- If you own an apartment building or duplex, consider free rent for the caregiver as partial fee for services. (I even negotiated a low rent for a room in the home of an associate of mine for our full time live-in-caregiver).
- Perhaps pay for their participation in certification renewals and AD trainings and respite care programs.
- If you have unoccupied bedrooms, allow a caregiver to live in your home as part of the compensation.
- Simply ask a caregiver who you really think would be beneficial for your AD patient, "How can we work this out?"
- **Think outside of the box!**

If you have any creative negotiating suggestions, I would love to hear from you. Please contact me:

my website, www.stolenbyldking.com.

blog post page, <http://stolenbyldk.com/lets-talk/>

or email to, stolenbyldking0@gmail.com.

CAREGIVER BLUES

When you keep doing the same thing, you will inevitably get the same results. Like many people, I was convinced that obtaining caregiver services from referrals was the best and safest way for us to recruit caregivers. But it simply wasn't working for us. The referrals weren't generating the caliber of caregivers that we envisioned for our dad. As shared earlier, I do take some responsibility for this situation. After approximately seven years of doing it my way, I opted to try the suggestion I had ignored in the past to place an advertisement for a caregiver in the paper.

To my surprise, the advertisement generated an overwhelming response. I received around 80 to 100 calls. Quite honestly, I lost count. The calls were incessant and lasted for about three weeks. The ad was only posted for four days: from Thursday to Sunday. The following is a draft of the advertisement that I thought would generate a pool of people with the potential training and experience we were looking for in a weekend relief caregiver:

Seeking a Certified Home Health Aid for
Private Duty, 24-Hour Live-in Position in
Baldwin Hills, Weekends only. Car required.

About one-third of the callers didn't have cars. Approximately one-third didn't have any type of certification such as Certified Nursing Assistant or Home Health Aide. Approximately one-third lacked significant communication skills. We ended up interviewing four. Our goal was to hire one and to stay in communication with the remaining ones who met our qualifications as a backup caregiver or floater.

This was a very rewarding experience, and for the first time allowed us to be in the driver's seat. We did hire an individual and have a file on the other caregivers of interest.

For your convenience, I have listed each caregiver tool in an appendix at the end of *Stolen*. The tools can be used individually, or in a group or team process. They include the following:

- Caregiver Profile for AD Patients-Appendix B
- Family Strengths Assessment-Appendix C
- Sample Interview Questions for AD Patients-Appendix D
- In-Home Care Agreement-Appendix E
- Daily Report Log-Appendix F

The In-Home-Care Assessment for Caregivers completes the recommended Assessment Components for In-Home-Care for an AD patient. With the Patient's Life Cycle; the Patient's Strength Assessment; the Family Strengths Assessment; and the In-Home-Care Assessment, you are almost ready to design a PADCP for your patient.

Once more, I need to share this: You must be prepared to continually make changes and adjustments in your PADCP to compensate for the constant behavioral and physical changes of the patient due to the disease.

In my opinion, the primary areas impacting the AD patient's life are physical, functional, social, sensory, emotional, and communication, regardless of the progression or stages of the disease. First, I want to discuss these six areas in order to increase your awareness about how they impact a patient's PADCP. I advocate that you, too, focus on these six areas as a guide. The following are the six areas and their influence on our dad's life, and hence addressed in his PADCP.

CHAPTER 8

SIX AREAS IMPACTING THE AD PATIENT'S LIFE



PHYSICAL AREA

Thinking out of the box in context to serving the AD patient's best interest is invaluable. For instance, changing and rearranging the items and furniture in the home facilitates independence and may enhance your patient's ability to function independently for an extended period of time. Staying in their familiar environment tends to reduce stress and confusion, and encourages a sense of success and accomplishment in their daily living activities. For example, at one time, our 91-year-old father loved taking a bath and luxuriating in the bathtub. Once he could no longer get in and out of the bathtub on his own, we chose to make adjustments to accommodate Dad's bathing enjoyment. To facilitate this, my brother and I purchased a reclining bath lift. It is battery operated. Dad was assisted with getting into the bath lift chair. With a push of a button, Dad was lowered gently into the water. Once the bath lift is lowered into the water, the back of the lift will recline into one of three comfortable bathing positions.

He loved it! He got to feel pampered and we were ecstatic that he is clean, smelling fresh from the aromatherapy products, and relaxed. With a push of the button, the bath lift chair is raised up for him to receive assistance to exit the bathtub. I believe this bathing activity contributed to Dad sleeping all night in the early stages.

Prior to its installment, the live-in-caregivers noted that he did not sleep through the night. Instead he was often up and wandering in an agitated state. I've mentioned the importance of observation and its significance in identifying AD symptoms in the early stages, and in recognizing the behavior changes and making the adjustments necessary in meeting your AD patient's needs when symptoms escalate. The timing of a medical evaluation can either put you in the driver's seat or have you fumbling to chase after and catch up with the thief who stole your loved one from you. So, paying attention to your elderly parent, sibling, friend, or spouse is key – as well as awareness of the ten warning signs for AD. I have learned that outbursts of agitation, aggression, and tantrums are Dad's way of seeking self-protection. When we noticed him having difficulty getting in and out of the chairs and off the sofa, we replaced the chairs in the breakfast room with the dining room chairs that are higher. This simple change allows him to be able to sit down and get up on his own much easier, while maintaining his independence.

The guest bathroom is no longer exclusively for houseguests, instead it has been customized and designated for Dad's use. A higher portable toilet seat has been placed over the original lowboy toilet to make it easier for Dad to use that bathroom. Dad spends a great deal of time daily in the den that is very close to the guest bathroom. Allowing Dad to use the guest bathroom rather than rushing him to his bedroom has significantly reduced accidents. This seemingly minor adjustment has made all the difference in the overall mental state of both Dad and the caregivers.

In addition, all area rugs have been removed from the rooms in his home. Handrails have been placed in the shower and bathroom tubs used by Dad. It is mandatory for Dad to use his walker at all times – inside and outside his home. Many glass coffee tables and accessories have been removed or replaced. An ottoman was brought in for Dad to elevate his legs whenever he sits down in the den to reduce swollen ankles, a circulation problem. Later, a recliner chair was purchased to replace the ottoman in the den and Dad loves it!

Thinking ahead about future adjustments, the recliner chair will facilitate transitioning him, if or when the time comes. It currently functions as a comfortable chair that allows his legs to be elevated, a bed for naps, and adjusts into two additional positions. We are also considering a stairlift for Dad to enter and exit his home since there are 16 stairs to the front or back door. Although the home decoration is not as stylish and pristine as it once was, these changes have facilitated safety, comfort, and independence for Dad in his home, and reduced stress for both he and the caregiver. All of these changes were simple, practical, and functional, and they generated positive outcomes.

FUNCTIONAL AREA

For practical reasons, I've classified this category of daily living activities as bathing, dressing, eating, toileting, and sleeping as the more important ones because they can be the most challenging due to the progression of AD. In 2006, I designed a simple Daily Log for in-home-caregivers to enter their observations about Dad on their shift. It was later developed to include observed changes in Dad's behaviors involving anxiety, confusion, lethargy, insomnia, and eating patterns, most of which are constantly changing due to the progression of AD. It is the daily activities of bathing, dressing, eating, toileting and sleeping that we are trying to keep as routine as they were before the onset of AD.

BATHING

In 2005, bathing and showering activities had become quite difficult. Dad became angry and actually threw temper tantrums, refusing to bath or shower. He felt that he wasn't unclean, and secondly there was no point since he wasn't going anywhere. This seemed logical to him, and at least he was exercising his thinking skills, whether or not it made the best sense to us. Through communication and observation, my brother and I discovered that it had nothing to do with his rationale of "why take a shower if I'm not going anywhere", but everything to do with the discomfort he felt having to get up when his bedroom was cold and take a bath or shower in a cold bathroom. It was uncomfort-

able for him to dress and undress because the temperature of the room was not conducive for him, although it felt fine to all of us.

We were able to overcome this objection by warming his bedroom and bathroom before bathing or showering. Also, we changed the bath and shower time to the evenings after he rode his stationary bike. We also offered him an incentive of one of his favorite snacks after the shower or bath. We ran the bath water and had it waiting for him. And lastly, we escorted him to the bathroom in his bathrobe or with a towel around him to keep him warm. This spared him some embarrassment of a female caregiver having to assist him with bathing.

Currently, those stressful days of daily having to beg and cajole Dad to take a bath or shower are over. Observation was the key factor here. I hope I'm not beating a dead horse, but we had to see past what Dad was saying to get to the bottom of this challenge. It was through communication and observation that we were able to overcome this challenging issue.

DRESSING

In 2006, Dad was selecting what he wanted to wear every day, which was mostly activewear. Currently, his clothes are laid out and he puts them on with assistance from the caregivers. He has trouble with the dexterity of buttoning clothing items. So he wears pullover tops and pull-up pants with elastic waistbands or Velcro so that he can do it himself. He tied the laces on his shoes until about Spring 2012. He still needs assistance zipping his pants since his gait is off. Then we began to observe that the walker Dad used not only assisted Dad's gait, but it also assisted him with dressing by having him stand up straight while holding on to the walker, which balanced him when zipping pants and putting on jackets or coats. Dad always used to wear caps when he dressed casually in activewear. Now we've observed that he wanted to wear a cap whenever he left the house. If he forgets to ask for a cap or the caregiver forgets to give him a cap to wear, he becomes very anxious when he realizes that a cap is not on his head or with him. It is as though the cap is desired not only for

physical comfort since he is bald, but it is also needed for emotional contentment. The cap appears to have become Dad's security blanket.

It's more important to note that the implementation of adjustments is about the AD patient's overall well-being and not our convenience. Many caregivers do what's easiest for them rather than what's best for the patient. Thus you will notice that nursing homes immediately put diapers, or Depends, on all residents who may show signs of incontinence because it is convenient. This forces patients to depend on Depends for life.

TOILETING

It's true that toileting is the not so pretty aspect of caregiving, but it is a critical part of the AD patient's view of their character and self-esteem. It has to be handled delicately, with sensitivity, but firmly at the same time.

This has been challenging for us. In 2006, Dad was wearing men's underwear. Currently, he is wearing Depends. Incidents of incontinence primarily centered on urinating in his pants when sleeping, or not being able to get to the bathroom in time. We have implemented a practice of asking or taking Dad to the bathroom every two hours and definitely before leaving home. We did not want the Depends to be an excuse for him to urinate on himself.

Quite honestly, we have observed that he doesn't want to urinate in the Depends because to him, they're his underwear, and he wouldn't urinate in his underwear. Changing his bathroom for easier access has reduced some of the incontinence accidents. Since the toilet accessory of a higher seat has been placed in the guest bathroom, this reduces the distance he has to walk when he feels the urge to urinate. We use baby wipes to clean him up after a bowel movement as a preventive measure for infections, even though he still is able to wipe himself with toilet paper.

The second time that I saw Dad tear up was when he had an accident at church because he couldn't get to the bathroom in time. He was embarrassed and humiliated that his pants were soaked with urine. All I could do was tell him everything was going to be okay. He had an accident. "*We just need to get you in the car and home to clean up and change clothes*". I think that it was the tone of my voice that calmed him down. It didn't help that people sort of stared at us as we walked down the long corridor to exit the church. On another occasion, Dad had an incident when he could not hold his urine, and this time he appeared not to have had any regrets about it.



I received a call: “Mr. King took down his pants and urinated in front of the house.” I couldn’t believe my ears and yet this was the report given to me by the caregiver over the telephone one day. I said, “No, he didn’t.” I felt a range of emotions – from shock and dismay to embarrassment. I even remember asking if any of the neighbors saw him do this ordinarily despicable act. The caregiver calmly described the following incident:

She took Dad out for an afternoon ride. Upon returning home and helping him out of the car, they prepared to go up the 16 steps leading to his front door. Dad suddenly exclaimed that he had to use the bathroom. She tried to convince him that he was home and he just needed to go up the stairs and turn left to the guest bathroom. But Dad retorted, “I have to go now!” A man pulled up in a car and saw Dad fumbling with his pants. He saw her struggling with him and asked if she needed any help. She replied, “No, I can handle this.” She proceeded to assist Dad by gently pulling down his pants and allowed him to urinate in the front of the house.”.

On one hand, I was so grateful for a trained, experienced caregiver who seemed to be in total control of this challenging ordeal. Some caregivers may have personal problems dealing with urine and/or bowel incontinence. This is an example of why it is recommended that you address incontinence issues when interviewing for a caregiver. This situation could have been compounded and escalated into a scene with an untrained or inexperienced caregiver. Then, on the other hand, I kept thinking, I can’t believe it! Dad lives in a nice residential neighborhood. Did people driving by see him? Did a neighbor happen to look out the window and observe him? Could the caregiver have taken him to the side of house? Then it hit me – Dad had to go to the bathroom right then in the moment. He even said, “I have to go *now*.” AD patients live in the *now*. What does that mean? Living in the *now* means that his mind no longer edits behaviors. He does not live in his head intellectualizing things and trying to determine what protocols and standards are the status quo.

Dad's lack of control and uncensored behavior was definitely a symptom of the disease. And at least he had the presence of mind not to want to urinate in his pants, or should I say, in his Depends. We've accepted the fact that we just have to roll with Dad in the "now" and that's what we do. We are definitely not advocating ignoring standard social behaviors, or behaviors that could harm Dad or someone else. We will continue to expect Dad to use the bathroom, but we will also be prepared for when he's not able to make it and the same with every other aspect of his life impacted by AD. For example, many of Dad's incontinence issues were stabilized by making the bathrooms in his home more accessible and user friendly for him. Also, we started to remind him to use the restroom before leaving the house as well as before returning home when on an outing which reduced incontinence incidents. We also ask the caregivers to take him to the bathroom every two or three hours during the day. But I never would have imagined that our dad, a proud, debonair man, with formidable hygiene rules and bathroom protocol, would urinate in the front yard with no hesitation. *Snap!* That was before AD.

Although we now keep a bag with incidentals such as a urinal, Depends, paper towels, and hand sanitizers, in the car, the bigger lesson for me is that *it's not about me*. In the latter stages of AD, many patients no longer even feel the urge to urinate or have a bowel movement. Hence, urinary and bowel incontinence are common occurrences. When this occurs, you really need to consult with the doctor to see if the incontinence is caused by other medical problems. Do not let doctors simply dismiss incontinence as inevitable with aging.

It is important to pay attention and try to recognize and identify the triggers that may cause anxiety and fidgetiness in a patient. For our father, the urge to go to the bathroom is one of them. Often times I notice a look of anxiousness on his face, and I'll ask him if he has to use the bathroom. More often than not, he will say yes! I don't know why he won't tell me he has to use the bathroom first. But it is what it is, and it could be many things.

Remember that their brain is no longer functioning normally. So your expectations have to adjust accordingly. Do not resort to bashing or reprimanding. Try not to demean them unintentionally or intentionally. These patients are adult human beings who deserve sensitivity and respect. And foremost, the impact of the reprimand affects them emotionally and psychologically in the “now,” but will not be remembered consciously minutes later. Unfortunately, the damage is done, which manifests in their expression and body language. I sincerely believe that our job as caregivers is to leave them with their dignity in place because the thief takes everything else.

Another phenomena for us linked with incontinence is that many falls for AD patients occur late at night or in the early morning hours, often when they get up to use the bathroom. Dad had fallen around 3 a.m. He was either going or coming back from the bathroom. So we tried to use a bed alarm similar to the ones used in a nursing or convalescent home to alert the caregiver when Dad got up to use the bathroom. We wanted to make sure that he uses his walker when he gets out of bed to go to the bathroom. The only way we are assured of this is if the caregiver is there to enforce it. The bed alarm really didn't work for the caregivers because the alarm activated with the slightest movement Dad made. We finally resorted to using baby monitors, which have been effective when the caregiver turns it on at night.

Closely related to the incident involving our dad falling in the early morning hours, this same caregiver failed to inform my brother and me until the following day or log-in the incident. These are some examples of the lax and negligent activities of untrained caregivers. Supposedly, most professional homecare agencies or registries carefully screen and conduct in-depth interviews, do reference and criminal record checks, verify training and work experiences. They also insure for professional liability, are bonded for damages and losses, provide workers compensation, and train their caregivers. They have standards that they convey to their in-home-care providers such as dressing in uniforms, clocking in and out at specific times, and not allowing personal visitors in the patient's home.

Although most agencies state that their fees are reasonable and are based on the condition and needs of the client, most fees are very expensive for working and middle-class people. So, often people such as me and my brother set out on their own to find a qualified caregiver who hopefully is more affordable, without sacrificing quality. Sadly, our experience has been that the level of professionalism and sophistication is often not the same with independent caregivers not registered with a registry or agency as with those registered with an agency.

Having said that, I did experience quite a few caregivers, such as this one, registered with an agency or previously registered, who lacked the appropriate professionalism and finesse. This illustration is a personal example of a live-in-caregiver who literally interpreted live-in to mean she could dress whenever she wanted to. She got up and dressed and fed our dad. However, she thought it was acceptable to sit around in her robe and house shoes. Did I mention that she was sent by an agency?



I also learned that all agencies aren't the same. There were a couple of other things this caregiver did which indicated a lack of training, which I assumed she received from the agency. "My assumption" is the key in this discussion. The moral of this story is assume nothing. Whether a caregiver is hired from an agency or not, you should have your own list of rules and regulations for your house and be prepared to train the perspective caregiver to meet your expectations of care.

SOCIAL AREA

Another one of my father's expressed triggers is the sense of loneliness and isolation he feels when he's around people, and is left out of the conversation or the activity. He has said that he feels "lost" when people are talking around him and do not include him. So we have learned the importance of including Dad in our conversations even though many of his responses may not be connected to the conversation. Equally important is for caregivers not to react to these responses as if they are not related or strange. My recommendation is to simply acknowledge what your AD patient has said by saying, "*I understand*" or "*okay*". The idea is to keep them involved and feeling like a participant in the conversation. I suggest that you just flow with the conversation as normally as possible, even if the subject of sex comes up. And Dad does bring up the subject!

I can definitely attest to reports of Dad's loss of inhibitions with the opposite sex, and his expressed desire for closeness, particularly sex. Caregivers have reported on a number of occasions Dad's request for a kiss or sex from them. They report that he asks very politely, however. When told "no," most of the time he says "okay" and forgets about it, although there are times that he tries to discuss the proposal and tries to persuade them. Most of the time, Dad can be redirected. I find it interesting that AD steals so much from patients and yet they still express very strong emotions, desires, and feelings. The desire for sex is a cry for affection and human companionship – it is a primal drive. I can only imagine Dad's longing for intimacy after having been married 58 years to the woman he loved and whose company he enjoyed.

ON SEXUAL ACTING-OUT

I've often wondered why conversations about sex seem so alluring and seductive, especially when people are whispering and laughing. So I decided to broach the subject of sex with a determination to be serious and professional. Sexual requests from my dad directed to the caregivers seemed to have occurred more often during his earlier stages of his diagnosis, but still continue even to this day. What I've found to be so captivating is that my father, probably similar to many other parents, was always characterized as a very conservative and reserved person, at least from our observation. The fact that he could appear so sexual at 90 years old was a little embarrassing at first, yet very humorous to me.

Curious about Dad's seemingly unusual behavior, I sought out to research the matter. I have learned that an AD patient has the same drives and desires as the rest of us. But, as a result of the disease, some AD patients have problems describing or acting appropriately on their sexual urges. Many patients develop a much stronger sense of sexuality, a condition that is often referred to as hyper-sexuality. In these cases, changes in the brain are thought to cause AD patients to lose control and inhibitions, resulting in behaviors that are disturbingly different from anything that you may have ever seen or heard of prior to the onset of the AD symptoms.

I never would have thought that our father would be asking for sex, or intercourse, as he often refers to it. Then again, it's a natural drive and as I've mentioned often throughout this chronology, Dad is physically very healthy and strong except for the damage that AD had caused, so why wouldn't he have a desire for sexual relationships? We think Dad mistakes the caregivers for Marguerite, his wife, since they are living in his house and taking care of him just like my mother, Marguerite did.

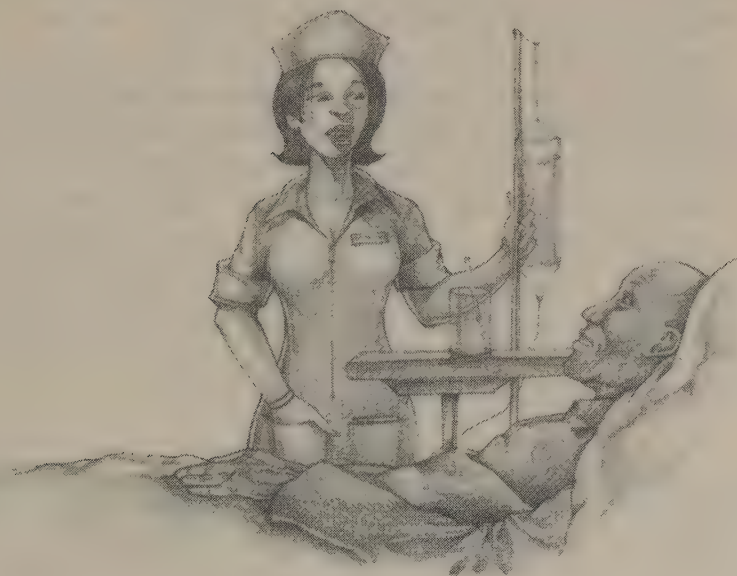
An untrained caregiver may have taken these sexual advancements personally. Inappropriate sexual statements or advancements from an AD patient are not considered sexual harassment because

the person does not have the presence of mind to inflict harm on another person. It must be viewed as an expression of the disease even though the desire may be real. A caregiver trained in working with AD patients knows how to redirect the patient by simply saying things such as, “No, not today Mr. King,” or “Here, have some delicious fruit I’ve prepared for you”. In other words, if the caregiver changes the subject or gives the patient something to take his mind off the subject of sex, oftentimes he will forget about it.

When I took into consideration Dad’s deterioration or regression in other areas of his life, it was quite plausible that he, too, would regress in the area of social etiquette. I’ve illustrated a number of these sexual incidents because of their innocence and obvious absence of malice in Dad’s statements. The incidents are recorded by the caregivers who are required to do a daily report on his daily activities (see: Daily Report Log, Appendix F). The following are a few summaries of the caregivers’ brief sexual encounters:

- Dad asked a caregiver for a kiss. She said he walked towards her without his walker. This scared her very much. Dad is 6’2” and can’t stand straight up without his walker. She ran out of the house and locked Dad in the house. Then she called my brother and sat on the front porch until he arrived. When my brother inquired about the incident, Dad denied it. This incident resulted in me asking myself, “What kind of training did she receive and where?” To leave Dad in his home unsupervised was very unprofessional and could have resulted in a health and safety issue.
- A caregiver reported that Dad knocked on her bedroom door around 2:30 a.m. and asked her, “Is it time for sex yet?” She replied, “No, Mr. King, now go back to bed.” Dad said, “Okay!” closed the door, returned to his bedroom, and drifted off to sleep.
- After major surgery, Dad was placed in the Intensive Care Unit for approximately seven days. One day, a nurse asked me and my brother to leave his room in order for them to perform a particular procedure. When the nurse came out of

his room, she was smiling, and said, "Your dad is something else." Then she proceeded to tell us that Dad asked her to have intercourse. She responded, "I can't do that, Mr. King!" Dad replied, "Why, you don't know how?"



When these sexual improprieties occur, my brother and I apologize to the caregivers on Dad's behalf. Most trained caregivers report that they know it is the AD causing the verbalizing and it's never been reported that he's been physically aggressive. Still, there were a few unethical caregivers who alleged sexual harassment. We had one who threatened to sue. It wasn't as if Dad badgered her or instilled fear in her for her safety. She had become disgruntled about another issue and decided to retaliate with an allegation of sexual harassment. She obviously forgot that she had previously reported the incidents and had made light of them. Although we didn't think that it would become a viable legal matter, we consulted with an attorney anyway just to be prepared. Ironically, we never heard from that caregiver again.

We also mention this possibility of inappropriate sexual statements due to Dad's illness in our interview process (Interview

Questions Tool, #12). I suggest that you do the same, so that caregivers are clear on what could occur during their shift with the AD patient. However, again a knowledgeable and experienced AD caregiver would know this.

SOCIAL AND SENSORY STIMULATION

You may have a loved one who was a very social person in their recent past and still shows signs of enjoying people. He or she may benefit from some of the adult daycare centers or senior centers for dementia clients. Many of these places could be very beneficial to contributing to meaningful leisure time, thereby alleviating some of the signs of anxiety, depression, and paranoia as a result of boredom. When AD clients have too much leisure time or time doing nothing, they show many of the signs previously mentioned. Our dad definitely becomes anxious when he is bored.

Too much leisure time adds to the AD patient's feelings of being devalued as a non-contributing family or community member. Many studies show that most people have an innate desire to be social. This desire for closeness doesn't vanish because they have AD.

I think my Dad is definitely one who desires socializing. I also believe that activities that a patient may have practiced repeatedly may be preserved in their memory and trigger either good or bad feelings associated with the particular experience. For example, I have observed that Dad enjoys shaking hands with men. He has a strong grip and enjoys hearing men comment about his strong handshake. In addition, I think that the act of extending a hand to greet him communicates that he is recognized and worthy of their attention. Subsequently, one of the reasons that I want our dad to go to church for as long as he is physically capable is because he is always pleasantly surprised by the number of parishioners who acknowledge and greet him there. I have observed that he especially enjoys the kisses on the cheeks from the women parishioners. This small show of affection is vital to him and his well-being, and I don't want to steal that from him.

SENSORY AREA

At some point in the progression of AD, many patients scramble the processing signals of sensory sensations, such as: sight, sounds, odors, tastes, textures, and touch. It was in the earlier stage of AD that I observed that Dad could not feel his keys or his wallet in his pockets. When he put his hand in the pocket, he would say that nothing was there because he couldn't identify the sensory feeling of the keys or the wallet. This sensory loss became a major concern, as it also occurred with money in his pocket.

Dad started the repetitive activity of taking his wallet in and out of his pocket, and then taking his money in and out of his wallet, which resulted in him losing money. Money was often found on the floors where he was standing and around the cars he was riding in and returned to us. We had to stop giving him money and his wallet. We had already taken the keys to his house for fear of them being lost. This action disturbed him at first because I am sure he felt items were being taken, a.k.a. stolen, from him. Eventually, he stopped noticing the absence of money, wallet, and keys in his pocket. However, on occasions, he still checks his pockets when we're out and comments that he doesn't have any money on him.

I think Dad enjoys the motion of a car when he's being driven around. He comments on the speed of the car, green and red signals, sirens, and people standing or walking on the streets. He even notices and comments on the size of some people. I don't know how many times he has said, "Gee, she is a big woman," or "Boy, that's a big man!" Riding in a car definitely stimulates our dad's senses, but then it always has. He drove the best and kept his car waxed, spotless, and full of gas. It was a source of pride and freedom, so you can see why he associates good feelings with riding in the car. He also enjoys eating good food. And he eats everything and lots of it. Clearly, Dad's sensory feelings for tasting and enjoying good food are optimal. It's as if what he gave his attention to in his life remains a source of enjoyment however remote it is from what it is now.

Our current caregivers are constantly stimulating Dad's hands with sensory exercises using stress balls, terrycloth, colorful socks, blocks, and magazine exercises where he tears out pictures he likes - in addition to his daily ROM (Range of Motions) exercises. Pleasantly surprised on day, I heard the caregiver refer to Dad's walker as his car. I thought that was brilliant. Dad has never been too excited about using the walker. In fact, prior to her reference to it as his car, if he had his choice, he would leave it behind and amble off severely bent over without it. She turned walking with the walker into a tangible activity. She tells Dad to steer the car straight, or to turn the wheels of the car one way or the other. I have observed that Dad really does look more enthusiastic driving his *walker-car*. These are examples of thinking out of the box, which, if you may recall, is one of our Caregiver Profile Characteristics. Closely related to the Sensory Area is the next component.

EMOTIONAL AREA

Emotional awareness is the ability to experience the full range of human feelings: love, joy, anger, fear, sorrow, sadness, compassion, passion, and empathy. As AD progresses, many patients lose interest in familiar activities that previously brought them much joy. Consequently, a major task is to keep them stimulated throughout the course of each day, which can be very challenging. This requires creative thinking and participation.

Although medical research tells us that the brain cells are dying, I believe that in the Early to Middle Stages of the disease, we should still try to stimulate the brain. Many of the sensory stimulants such as sound, sight, smell, taste, touch, laughter, and problem-solving can give an AD patient more joy and contentment. I have observed that small things can make a big difference. For example, not only does Dad have a big appetite, but I've also noticed that he appreciates the presentation of food. He notices when food is colorful and placed on the plate in an orderly manner. He will comment, "Boy that looks good." After eating a good meal, he will say, "That was tasty."

Another source of joy for him is music. He enjoys music! So I take him to my church, because he truly appreciates the choir and appears alert during the service most of the time. In keeping with his interest in music, I encourage caregivers to put the radio on rather than the TV.

I mentioned earlier that Dad has a compulsive disorder (as a result of AD) for folding and refolding napkins, tissue, or anything that is touchable and foldable, so we incorporated this activity into his PADCP. We encourage the caregivers to let him fold the clean clothes after they are washed and dried for as long as he can. It is also one of his sensory triggers that we've identified, which transforms this behavior into a positive, productive outcome, making him feel contributive, and a participant in his home.

I believe there is a great deal of "life" in many AD patients well into the Late Stages of the disease. Many doctors in the medical field are unaware of it because they only see a patient for a brief period of time and in a sterile or strange environment for the patient. These doctors and clinicians don't get the opportunity to see how alive patients become when they are engaged or stimulated. I advocate that as primary caregiver, we become their historian, responsible for observing and noting some of these defining moments by journaling about their experiences. It could end up being a wonderful keepsake for you. If you pay attention to them, many of the things that they say and do actually reflect some degree of critical thinking skills and awareness.

For example, one day I visited Dad and the caregiver reported that Dad wanted to sleep with his hat on. She told him you can't do that! He replied that he could do it if he wanted to. It was an 'ah ha' moment for the caregiver because she said she realized that he was right. He could do it! So she decided, why not let him sleep in his cap? If it was uncomfortable, he would simply remove the cap. I am grateful that the caregiver didn't get into a verbal altercation, which she would have definitely lost, over a cap. They say you never win an argument with an AD patient.

Dad still has a great sense of humor and a wonderful hardy laugh. We try to find some of the old comedy sitcoms on TV and videos that help to kindle his laughter. Daily dialogue with him normally generates some humor. Many of Dad's verbal responses are rather confusing, and he, too, has laughed at them on many occasions. One of his favorite sayings after a rather ambiguous statement is, "I'm just kidding." From a medical perspective, laughter releases specific endorphins in the brain that have a healing effect on the body. Laughing does matter! So we aim to keep Dad laughing.

We now have caregivers who really converse with Dad. Subsequently, we are actually observing that Dad is talking more, which leads to humor. This is why hiring caregivers with a joyful spirit and a sense of humor is important to us, and a factor in our Caregiver Profile.

We have come to realize that even though we thought we were empathic to Dad's illness, often times my brother and I had unrealistic expectations. Frequently, these expectations can trigger frustration, verbal agitation, and physical aggression in Dad. In an effort to initiate conversation with him, a simple question about what did you eat for breakfast or lunch would bring on a sad expression. At the time his lack of response was not understood as well as his forlorn look.

Now, I clearly understand why a simple inquiry about lunch caused him stress. He simply didn't remember. As hard as it may be to comprehend, Dad didn't remember what he ate an hour ago. The fact that he didn't recall, caused him major frustration because he didn't understand why he did not remember. This confusion often caused him to be very sad. I have learned to let go of hinting or trying to prod his memory. The memory of lunch is gone. It only causes the patient anxiety, embarrassment, and frustration to ask about or expect them to remember what he ate that day and many of the daily activities. This is why it is crucial for in-home-caregivers to log the activities in the Daily Report Log.

As previously mentioned, one of the first times Dad cried after the diagnosis of AD was when he had to stop driving. He lamented, "What will I do without a car? How will I get around?" I promised him in 2006 that he would always have transportation whenever he needed it or wanted it. Therefore, since 2006, it has always been a condition of employment for the caregiver to have a car and proof of insurance. He appears to need to leave the house and go for a daily ride for his emotional satisfaction. It can simply be an errand to get gas or to go to the post office or visit a friend. One day I arrived at Dad's and I noticed he was sitting in his favorite chair with his hat on. I asked him where he was going. He said, "I don't know, but somewhere, I hope!" His response clearly indicated his desire to get up and out of the house.

Today, Dad continues to walk down a flight of 16 stairs in order to leave his home, and up 16 stairs to re-enter it. We are very protective as he navigates this process. He is always accompanied and assisted when appropriate. In 2006, he did it independently. Currently, he holds onto the stair rail with one hand. Sometimes he places both hands on the stair rail to pull himself up each stair step. Other times, a caregiver holds his arm while he has the other on the rail when he's going up and down the stairs. Navigating these stairs is still a remaining skill that we don't want to take away from Dad prematurely. We know he needs to go *somewhere*.

COMMUNICATION AREA

Eventually Dad will lose his ability to verbally communicate, which can cause feelings of embarrassment and dehumanization. Currently, he has communication episodes riddled with confusion and disorientation. Increasingly he is losing the ability to effectively articulate himself because he can't recall the words to describe what he is trying to say. Often after he struggles and finally finds the word in his mind, he then labors to actually **say** the word. I try to suggest the word(s) he is looking for and sometimes he chooses the right word; at other times he just lets it go. The hopelessness I feel when I can't help him, I try to conceal for Dad's sake. But do

not underestimate an AD patient's ability to read your facial expressions, tone of voice, gestures, and signs of impatience because what they feel or sense remains a part of their awareness. Be cognizant of this and always be compassionate and patient. When Dad feels that we are becoming impatient with him, he becomes embarrassed and anxious. When Dad doesn't comprehend verbal instructions, we find it beneficial to stop, look him directly in the eyes, speak slowly, and demonstrate exactly what we want him to do.

There was an instance when Dad was standing right by a chair, and when he was instructed to sit down, he would ask, "Where?" So, we had to point to the chair and tell him to sit in *this* chair. Most sources report that in the latter stages of AD, 90 percent of communication is nonverbal with AD patients. Some caregivers put pictures on the doors and walls to communicate the critical areas in the house. For example, they may post a picture of a toilet and/or a picture of washing hands on the bathroom door, or a picture of a bed on the bedroom door, or a picture of a person eating at the breakfast table. I'm grateful that this has not been necessary for Dad, but if and when the time comes, we will use pictures to help us communicate with him.

Definitely don't underestimate their ability to hear. Many doctors report that hearing is often the last thing to go. I can't tell you how many untrained caregivers I've stopped dead in their tracks from talking about Dad or reporting something he did right in front of him as though he was a child who needed to be chastised. These are the types of caregiver behavior that can trigger outbursts from some AD patients. They don't want to be treated like a child.

The significant physical, functional, social, sensory, emotional, and communication areas identified for our father may differ significantly from the ones identified for your patient. That's why an individualized PADCP is essential. It's based on your patient's environmental, cultural, and unique personal needs.

For example, if my dad had been a golfer, I probably would include taking him to the golf course a couple of days a week to hit a

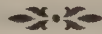
few balls or to talk to some of his buddies at the golf course. Maybe we would even have lunch there. Perhaps, socially your patient would really benefit by going to a senior center or an adult daycare daily. My Dad did not enjoy that environment.

Many of the benefits that Dad enjoys in the care of his own home wouldn't be available in a residential or convalescent home, largely due to staffing and liability issues. In his home he gets 24-hour one-on-one attention and supervision.

Finally, the PADCP for our dad! Using all four of the Assessment Components to develop our prototype, I designed the following PADCP specifically to meet the individual needs of Mr. Wince V. King, Jr.

CHAPTER 9

THE PERSONAL ALZHEIMER'S DISEASE CARE PLAN (PADCP)



Each task listed in the PADCP has a specific purpose and objective to achieve a goal. Our PADCP for Dad meets his safety needs and allows for adjustments for any significant deficits. It minimizes or reduces stress; optimizes his functioning; maximizes his successes; and promotes positive emotions. It is designed as a strength-based concept, which required me and my brother to make fundamental changes in our attitude and in his physical environment as the disease progresses. This facilitated our ability to compensate for the ongoing and progressive behavior, functional, cognitive, and physical changes.

The Personal Alzheimer's Disease Care Plan (PADCP)

Column1	Column2	Column3	Column4	Column5	Column6
MORNING	CAREGIVER TASKS	HOUSE PROTOCOL	PERSONAL PROTOCOL	MENTAL STIMULUS	PHYSICAL ACTIVITIES
	Rise, shower, and dress in scrubs before patient	Open window shutters, let patient assist daily (as long as possible)	Patient brushes teeth	Play music	Have patient stretch arms up & extend forward
	Layout clothes for patient	Check house temperature (keep warm)	Patient washes face, bathes & moisturizes body	Encourage patient to pray and bless food (breakfast)	Help patient to do leg exercises
	Clean patient's eyeglasses and put on patient's face	Heat master bedroom and bathroom	Patient body exam by Caregiver (look for bruises and other bodily changes: a cut, abrasion, etc.) Document in log	Engage Patient in stimulating conversations	*Have patient ride stationary bike anytime
	Assist patient with dressing	Take patient to bathroom upon rising	Patient dresses	Have patient count stairs when using them	Assist patient walking down stairs when leaving home and walking up stairs upon returning home
	Assist patient with putting on and lacing shoes (put on and lace them when he cannot)	Record in daily log morning activities, observations and all and anything unusual	Set up walker for patient's use. Make sure patient walks with walker at all times.	Sing along with music and encourage patient to when applicable	Take patient out on short walks
	Supervise patient with washing face and brushing teeth (set up toothbrush with toothpaste)	Call primary caregivers regarding any unusual occurrence with patient or house issues	Administer water to patient to break fast	Encourage looking at photo albums as an activity	Encourage patient to assist with household chores: folding laundry, and putting away.
	Prepare breakfast and include Ensure drink with meal	Caregiver manages/answers phone and door calls	Shave patient every two days	Attend Church on Sundays (take Patient)	Have patient walk up and down stairs in house
	Make sure patient drinks water in the morning	Check for voicemail messages upon leaving and returning to house.	Wear clean clothes daily	Play checkers	Play checkers
	Give patient medication rationed by primary caregivers	Should patient fall call emergency paramedics first then call primary caregivers	Patients Hat signals Time To Go		*Therapeutic Ball exercise
	Check and make sure doors of house are locked		*Patient should always wear hat when out		
	Secure phones				
	Check voicemail messages, and respond accordingly				

AFTERNOON					
	Keep patient on bathroom visit schedule of every two hours	Patient must use walker at all times in home and especially when outside and on outings.	Prepare patient for lunch meal	Encourage patient to pray and bless food (lunch)	
	Prepare lunch meal	Play music throughout the day		Assist patient with identifying personal items & memorabilia	
	Log in/record in Daily Journal	Direct naps to napping area (avoid master bedroom)		Watch sports and engage patient in conversation.	
	Afternoon outing (take patient for a ride or on errand runs: grocery shopping, etc.)		Continue every 2 hour Bathroom visit until he retires for bed	Schedule restaurant outings	
	Keep patient hydrated with water	Have patient use hand sanitizers during the day		Sit on front porch, have patient speak and wave to passing neighbors	
	Manage house phone calls	Manage/answer house phone calls		Have patient count the stairs when using them	
	Walker is to be available for patient's use	Patient must use walker in house and especially outside and on outings	No water after ???		
	Temper water before bath/showers	Schedule patient's appointments for early or mid morning (he's more alert)	Put & set alarm clock on bed		
	Assist patient with washing hands	Notify primary caregivers when patient is taken out	Temper water before bath		

The Personal Alzheimer's Disease Care Plan (PADCP)

EVENING					
	Prepare dinner meal	Provide patient healthy snacks	Prepare dinner meal		Assist patient with undressing
	Prepare bath when necessary or patient desires (Apply skin care lotion to patient)				
	Assist patient with washing face Assist patient with brushing teeth	Continue every two-hour bathroom visits until patient retires for bed.	Assist Patient with washing hands		Assist patient with dressing for bed
	Assist patient with undressing and dressing for bed	Administer drinking water (none after 7 p.m.)			
	Assist patient with getting into bed		*Elevate feet when sitting		
	Elevate bed for patient's leg circulation				
	Activate bedroom monitors and bed alarm		Hand, arms, legs exercises		
	Patient body exam by caregiver (look for bruises and other bodily changes: a cut, etc.)		Check ankles and toes		
	Check ankles and toes carefully		Apply Skin care-lotion body to patient after bathing		
	Observe and document all changes regarding patient's physical and mental behavior. *(Call primary caregivers, paramedics)		Brush Teeth		
			Begin preparation for bed between 9:00 & 9:30 PM		
			Patient body exam by Caregiver (look for bruises and other bodily changes: a cut, abrasion, etc.)		
			Take Patient to bathroom before bed		

This plan was designed to meet the specific needs of our father. It is based on his: AD diagnosis; knowledge of the disease; expected or potential behavioral responses; personal observation of him; his preferences; likes and dislikes; his needs; his requests; and our personal desire to deliver quality care to him in his home. It is shared here to give you a foundation, a prototype from which to work and create your own plan. This is a tool. You can adjust, rearrange, or borrow some ideas, or you can create an entirely different plan. But **do** create a plan, a PADCP, that works for you, your patient and all involved.

That's why it is appropriately named PERSONAL AD CARE PLAN (PADCP).

CHAPTER 10

PADCP ALSO FUNCTIONS AS A LONG TERM GUIDE



On May 18, 2011, our dad turned 92 years old. He walked into the restaurant we chose for his birthday lunch, with his walker and the caregiver, looking very dapper. He had a margarita (with alcohol, I might add). He appeared to have enjoyed it immensely and it showed in the countenance of his face. I observed that he wasn't very verbal that day. In fact, he didn't finish his meal either. Actually in retrospect, I recall he was walking much slower than usual. Then I snapped out of it, and was grateful to simply celebrate another year of having him here, on this memorable day.

Dad really does appear to be in the Late Stage of the disease. I have observed many notable changes in him at this stage. He requires total supervision and assistance with most of his daily living activities. This should not be confused with the total care required in the latter part of the Late Stage, which routinely requires bathing and feeding a patient that is normally wheelchair bound or unable to walk or talk. Dad is walking, talking, exercising, and taking showers with some assistance. I have really tried not to get hung up with the symptoms in the stages, and use them solely as a guide, not a definitive tool.

I must admit that his 92nd birthday did help me to prepare for latter part of this stage. Those debilitating symptoms could manifest in six months, a year, or two or three years from now. My point is,

many are inevitable, pre-empted only by death. A PADCP allows you to see and project what you might have to prepare for or modify next. By no means am I suggesting that you become overly concerned and run out and make large purchases until it becomes necessary. I am suggesting that you think about ways to enhance your patient's comfort, safety, and quality of life in the home before an accident or episode occurs. It may put you in front of the ball, rather than chasing the ball. For example, it is obvious that Dad is becoming more fragile and his ability to navigate the stairs entering and leaving his house is becoming more difficult for him. We have contacted a contractor about the feasibility of installing a stairlift in his home, and have received an estimate of the cost if and when that time comes.

We have discussed purchasing a daybed for Dad's bedroom in anticipation of having the caregivers sleep in his room at night when the time comes. Currently, they have their own bedroom and bathroom with monitors, which enable them to hear his every move. We're discussing installing monitors and cameras throughout the house instead of monitors only in the bedrooms. I've considered, perhaps, landscaping the back yard or simply bringing in outdoor plants to make the yard more pleasing and stimulating to Dad's eyes when he sits at the breakfast table eating. In addition, the landscaping can be eye candy when he looks into the patio area from his bedroom, if or when he becomes bedridden.

In anticipation of Dad becoming more homebound, we've moved the furniture in the living room to allow him to look out of the large bay window to see neighbors or what's happening on his street. We've decided to replace the carpet in Dad's bedroom, which was soiled due to some incontinence issues that we have subsequently resolved. I know many primary caregivers similar to me and my brother have probably noticed a great deal of deferred maintenance in their parents' home. Pulling up old, faded or raggedy carpet and replacing it with hardwood floors and simply painting are examples of cosmetic changes that can make a difference for the patient now, and possibly in the future by increasing property values. Not to mention that it is just more refreshing.

Some major purchases or major improvements may involve a discussion around taking out a second mortgage or a reverse mortgage. Remember, the goal is to do whatever it takes to keep a patient in their home safely for as long as humanely possible. Taking patients out of their home prematurely is an agonizing sentence for many of them. Many patients feel tossed away and lose hope when removed from their homes. If you don't believe me, go to a convalescent home or nursing home and talk to some of the patients and listen to their stories. Keeping an AD patient in their home is not as difficult as many think if you have tools and can afford the help. A PADCP is one of the tools that will help you and the patient stay focused on the primary objective – to keep the patient safely in their home. I know I touched on it before, but quality out-of-home-care can be very costly.

A LOOK BACK

The process of revising and modifying Dad's PADCP when he turned 92 took me through nine years of memory lane. I recalled vividly Dad's 83rd birthday party in 2002. He was doing a little dating then. My brother and I hosted the party in his home. Dad was standing tall and looking good. People flowed in laughing and talking and appeared generally happy to just be there. Dad's home had been the source of many parties and affairs hosted by him and our deceased mother during last half of the 20th Century. Music filled the air inside and outside. A vocalist belted out songs reminiscent of their era. A good time was had by all.

All I could think of then in 2012 was, "What a Difference a Day Makes." Now, ten years later and Dad is a different man. Who would have thought it?

I've always believed that our mother's death was the event that triggered our dad's cognitive decline. However, fond memories and the assistance of about 2,000 daily reports from a host of caregivers assisted me in reviewing and identifying four milestone markers in the progression of Dad's disease. Ironically, the four major areas do correlate with the declining scores of the MMSE previously

disclosed, but here I will add more detail. They are: 2004-2006; 2006-2007; 2007-2009; 2010-present.

2004-2006

A year later after his 83rd birthday, in May 2003, Dad was bent over and using the assistance of a walker in order to stabilize his gait. He was showing signs of confusion. I took over doing his bills. We obtained the services of Lifeline, which provided a personal monitor to be worn around his neck. If any emergency occurred, Dad only had to push a button and a live person would respond to the need. The monitor was worth its weight in gold because of the peace of mind it gave us. We were particularly concerned about falls when no one was around.

We utilized the services of part-time caregivers who eventually worked five or six hours a day, five days a week. At one point, we even implemented a split shift of three hours in the morning, and returning to do another three hours in the evening. This arrangement allowed Dad the most independence, at that time, which was congruent with our strength-based PADCP, and an example of thinking out of the box. The caregiver would prepare breakfast and provide some companionship for Dad, leave and then return to prepare dinner and some additional companionship in the evening. He was able to be home alone at night. Dad was taken to Bible study once a week and attended church on Sundays. He still handled his money on a limited basis. In January 2004, Dad's MMSE score was 26/30. By June 2004, his MMSE score was 20/30.

2006-2007

I've mentioned numerous times that Dad was a relatively healthy man. But did I mention that he never was sick or ever had any type of surgery until November 2000? I had forgotten that when he was 81, it was recommended that he have surgery for a knee replacement. Of course, this surgery involved general anesthesia. This was approximately three months after our mother's death. I

now recall that his first memory loss incident occurred after this surgery. Could this have been the actual beginning of AD symptoms or was it *Postoperative Cognitive Dysfunction* (POCD)? This is a form of cognitive decline that may occur after surgery. Actually, the surgery on Dad's foot for gout in 2006 was his second hospitalization involving general anesthesia. After a stint in a rehabilitation/convalescent home, it was obvious that Dad required 24-hour care and the services of a live-in-caregiver. His memory and cognitive abilities had definitely declined. In fact, in November 2006, Dad's MMSE score was 19/30. Reportedly, there was no change in 2005.

I lived in Dad's home with the caregiver for approximately six months to acclimate him to the idea of a stranger living in his home. I'm still deliberating whether that was a good idea or not because Dad deferred to me often, which fostered alienation in the caregivers sometimes. Other times, they were very grateful I was there to resolve issues. During this period, there were reports of angry outbursts, opposition to bathing, and lethargy provided to us by the caregivers. Ironically, our first caregivers- who were independent contractors- were also lethargic. Oftentimes, AD patients emulate the negative behaviors of others. AD patients need positive stimulation, which is another reason they don't do well in convalescent homes and nursing homes unless they are seriously ill. When I moved back to my home, Dad called me on the phone almost daily.

2007-2009

A new caregiver ushered in this period and remained for over two years. She was the second primary caregiver to live-in five days a week. This was a challenging period due to the progression of the disease and the behavioral changes that manifested. Oftentimes the behavior problems exhibited by some AD patients, such as aggression, sleep disturbances, and incontinence, are the behaviors that hasten the decision of family members to institutionalize a patient. An experienced caregiver often knows how to respond to the patient's signals that precede many of the problem behaviors. These signals are often referred to as triggers.

Sometimes the caregiver is the problem. For example, Dad began to use some curse words or call people names that he had never used before. Profanity had never been part of his vocabulary. This was puzzling until we realized that he was hearing profanity in his home. This caregiver reluctantly had to learn how to care for our dad in the manner to which he was accustomed. She was asked to refrain from the use of profanity in Dad's presence. Resolutely, she did, and Dad's use of profanity ceased. The daily reports often pointed out incidents accusing Dad of making this caregiver feel bad by calling her names, the making of sexual statements by Dad, and claims that Dad woke up mean and extremely confused and uncooperative.

It was during this period that we realized that Dad's opposition to bathing and showering was directly associated with him feeling cold. Once we started heating the house before he woke up and before he took a bath or shower, it was no longer a problem. Even though the house seemed comfortable to us, we learned that Dad has chronic anemia, which would account for his discomfort, especially in the morning and evening. Also, because of the caregiver's report on his behavior, we had to stop Dad from attending a bible study class at his church that he had previously enjoyed and always looked forward to the interaction and sharing. The reports stated that Dad's behavior ranged from being inattentive, to lethargic, to disruptive on many occasions.

This was also the period when many of Dad's personal and home items came up missing. Later, I personally located items like vases and large decorative ashtrays that Dad had obviously hidden behind the couch and in closets. It was a contentious period because at first when things came up missing, we reluctantly looked at the caregiver. We later learned that it is common for AD patients to hide things. Again, this is the period that Dad's social security card and his California ID came up missing and have never been recovered. We really don't know whether Dad has hidden them or if they have been stolen. We only know for sure that they are gone. I must admit, even though there was a great deal of discord during this time, we were grateful that Dad had a caregiver who was taking him out almost daily, which we know was beneficial to his emotional sense

of well-being. In May 2008, Dad's MMSE score was 14/30. He was down five points since the end of 2006.

2010-PRESENT

In March 2010, we finally hired a caregiver who looked to have a good personality, seemed emotionally stable, and appeared to enjoy and respect Dad. She was knowledgeable about AD, and she knew not to take Dad's behavior personally. During this period, some significant changes began occurring. There are increasing incidents of Dad not recognizing me or my brother as his daughter and son, as well as not recognizing other family members. Dad stopped recognizing his home and he frequently needs to be guided to once familiar rooms in his home such as the bathroom or his bedroom. His motor skills are much slower.

Time passes, and there now are increased incidents of Dad requesting to be taken to the bathroom after he has already gone and relieved himself. He keeps saying he has to go, so the caregiver takes him, and he doesn't do anything. He's also eating much slower. In fact, often when you place a meal in front of him, you have to tell him to eat. On many occasions, he will say that he is eating. I don't know whether in his mind he's already eaten or if it just takes more time to register and connect the thought of eating with the actual act of eating. Increased also are the statements by Dad of feeling confused and mixed-up. His language is garbled and he does not understand simple instructions. One morning I observed the caregiver instructing him to get out of bed and put his feet down on the floor. Instead, Dad raised his feet. In March 2011, Dad's score was 6/30. It was down eight points since 2008. Our dad's progression of AD has been clear evidence of the inconsistent yet degenerative path of this intriguing disease.

As far as we are concerned, Dad is still going strong. We continue to focus on his strengths. In light of the serious cognitive changes, overall he is doing well navigating this disease. One day in August 2011, I drove over to his house only to find him not home. I decided to wait, and a few minutes later he and the caregiver pulled

up. When I approached the car, Dad said, “Hi sweetheart,” and got out of the car on his own. Then he proceeded to ascend those 16 stairs to the door of his home, with us walking very guarded and close behind him. As I watched, I thought, God willing, we will not have to remove him from his home – his last remaining possession.

GOING FORWARD

May 18, 2012, was a significant day. We celebrated Dad’s 93rd birthday. My brother and I decided to take him shopping and then to lunch at a soul food restaurant in an upscale shopping mall. Since these two activities involved a great deal of walking, Dad was content with us pushing him in a wheelchair we had acquired for these types of circumstances. He was alert, communicative, and looked good in his jogging suit. That day we purchased him two more summer jogging suits, which he loves to wear during the week. We also purchased a pair of dress shoes because I was certain he has quite a few more church Sundays to suit up for. Surprisingly, the caregiver also purchased him a t-shirt to go with his new jogging outfits. Dad ate well, but due to the large serving of food, he was unable to finish his meal. We sang happy birthday to him and he blew out the one candle that was placed on his birthday dessert.

My brother and I drove our cars and met Dad and the caregiver, and my sister-in-law at the shopping mall. On the way home, the caregiver pulled her car up to mine at a signal. I rolled my window down and waved to Dad and said, “Hello.” He looked at me, smiled, and in a very GQ manner said, “*Hey there!*”. I knew then that when I arrived home that afternoon, I was going to take a nap and then get up and conclude this chronology of our personal experience in trying to provide Dad the quality of care he deserves. It was clearly obvious that day that we were succeeding in this goal. Additionally, the attention he received from the caregiver was a testament to the difference *a caregiver with a calling* can make in a patient’s life.

Yes, this evening I was definitely concluding this story and preparing this manuscript to go to press, even though I knew there

is so much more to come and be shared with readers. I plan to blog about Dad, the progression of his AD symptoms; and how we are managing them; whether he will be able to remain in his home; offer suggestions; and share research updates.

Dad still continues to be physically strong and functional in performing many of his daily activities; but as you know now, the major determinant for AD is the loss of memory and cognitive abilities, not physical strength. This is something I have to keep reminding myself when I observe him doing his exercises, and kicking his legs up much higher than I will ever be able to do. I think it is just phenomenal, and it is absolutely a defining moment in my mind.

Quite frankly, Dad's short and long-term memory is almost gone. He remains ambulatory, brushes his teeth, and washes his face with assistance. He goes to the bathroom on his own, yet he is requiring more assistance. He has a very healthy appetite and feeds himself slowly, exercises daily, goes out on outings with the caregiver (though not daily anymore), attends church some Sundays, and still communicates. On the other hand, sundowning, incontinence, and insomnia episodes are increasing. His movement is slower and anxiety and confusion are increasing. His gait appears more difficult and a stairlift installed in his home may be more imminent.

We have decided that the "good news" is that at the age of 93, our dad still has a joyful spirit most days while he traverses this disease with persistence and fortitude. Even though Dad's last AD assessment in 2010 resulted in him being labeled with "severe cognitive impairment," I have observed him enjoying better moments, better days, and communicating better feelings. Often Dad reports that he feels fine, or good, or that things are going beautifully. One day, he even said, "I am blessed" in a conversation we were having. Little does Dad realize that these words are like music to my ears.

In October 2012, we hired a wonderful caregiver *with a calling* who possessed all of the characteristics in our Caregiver Profile. She recommended a previous co-worker whom she had worked

together with a previous patient who also had dementia. They seem to complement each other. They are both independent contractors. One is the weekday live-in-caregiver, and the other is her relief. They are happy and content with our daily flat rate, and receptive to the suggestions and recommendations embodied in our PADCP. My brother met them at the funeral of their deceased former patient. I should mention – albeit a rather morbid suggestion – that funerals and repasts can be a very resourceful way of finding good caregivers.

Think about it! It can be a credible reference when you hear the family members mentioning the caregiver for the deceased in the service or in the program as providing excellent care. However, in deference to the family, I suggest that you simply approach the caregiver and ask if you can contact them later about the possibility of working with another patient. Don't try to conduct a mini-interview at the funeral or repast. It is not the appropriate time.

Overall, Dad already has a better quality of life as a result of the quality of care of our current caregivers, and the quality of caregivers that my brother and I have become. The proof is in the noticeable behavioral improvement, his pleasant demeanor, and his verbal expressions of feeling good or fine or blessed. Based on our PADCP and the refined interventions and our open communication policy with our caregivers, they have a good understanding of what we are requiring and our expectation of their services and performance, and vice versa. Dad's current in-home-caregivers talk to him in such a way that he feels valued, feels cared for and cared about, and this simple act, subsequently, reduces many of his behavioral symptoms. As a result of these caregivers providing a level of quality care that is person-centered and very hands-on with him, the quality of their day improves, because many of Dad's behavioral challenges are stabilized, which I am attributing to their awareness of how to talk, and how to treat him.

Dad's behavioral responses to circumstances and situations are now circumvented because the caregivers now have a better understanding of what triggers a certain reaction and are able to monitor

both his and their own responses. How do I know this, you may be asking? The Daily Report Logs we require reveal much more than most caregivers realize. These caregivers in particular are more cognizant of understanding our dad, and of how to manage their reactions, which mitigates the previous behaviors to the puzzling changes in his conduct and cognitive abilities. They are aware of how their nonverbal expressions of shame, pity, or embarrassment communicate the same thoughts to Dad. This is a direct result of skills and knowledge. We inform, teach, train, and share in the responsibility with our caregivers. Of course now, it will be mandatory for all caregivers to read *Stolen* in order to familiarize themselves with our concept of quality care and the importance of the PADCP as our operating tool!

Dad still experiences episodes of catastrophic reactions, serious anxiety and confusion, and some incontinence issues. However, we have been able to identify the triggers for these random situations, and the incidents have been reduced significantly. As mentioned earlier, sundowning, insomnia, and incontinence are becoming the more challenging behaviors, which our current caregivers are dealing with creatively.

My brother and I work diligently with the caregivers on these issues because of deep concern for our dad and consideration for them as well. Insomnia and restlessness at night and in the early morning are serious behaviors that can cause sleep deprivation for the caregivers, as well as for Dad. It wears Dad out and several of the caregivers have terminated their services because of fatigue. Ironically, that has happened mostly with the weekend providers, who generally seemed less experienced and trained. I still believe these two symptoms, along with incontinence, account for many AD patients being admitted to out-of-home care facilities prematurely.

CHAPTER 11

RESOLUTIONS



A CALL FOR CAREGIVER EMPOWERMENT

Most of the caregivers we have hired have always expressed joy in caring for our dad because of his character and personality. It was the level of care that was an issue for us. Our current caregivers are actually knowledgeable about AD and those specifics unique to AD caregiving, which I think should be recognized as a specialized area of caregiving. Further, I'm advocating for certifications in AD care with designations as a AD Certified Nursing Assistant or AD Home Health Assistant. Minimally, I believe all in-home-caregivers registered with agencies and registries and In-Home-Support-Service workers in unions, should be trained in how to provide compassionate care to an AD patient. They could even be called AD-IHSS workers. There is going to be an urgent demand for qualified AD caregivers in the near future because people are living longer and normal aging is considered to be a major risk factor for getting this disease.

According to Delta's *Sky Mall* Magazine, we will experience an upsurge in in-home-care based businesses that will be targeting 78 million Baby Boomers in the near future. Oh, did I mention that I decided to celebrate our feat of finally hiring the two caregivers to complete our caregiving team for Dad by going on a vacation! Well, I immediately booked a flight to Puerto Rico to celebrate and I had a great time. I believe my *caregiver blues* are over. *I exhaled!*

I simply can't express it enough that Dad's current level of comfort, joviality, high spirits, contentment, and overall quality of care is the result of our current caregivers' professional integrity and joyful spirit. They know that AD is not simply a serious memory problem. It is a disease that attacks the brain, causing deterioration of the brain functions. They also recognize the importance of getting detailed information about Dad from us in order to keep his environment and his daily life and activities as familiar and consistent for him for as long as possible. I stress this because I was moved to write this memoir of sorts to assist others like me and my brother, who may find themselves at their wits end and fret with despair in their efforts to provide quality care. My intention is to provide insight while letting you know that there is hope.

By sharing our experience as primary caregivers, we are certain that you will be able to relate to many of the challenges, our emotional highs and lows, and empathize with the dilemma around money, good quality care for our father, and the lack of options. Further, perhaps *Stolen* will inspire you to put on your creative thinking cap and get busy developing a plan of care for your AD patient that is strength-based. Finally, we hope that you will join us in our effort to unite, strengthen, and support primary caregivers in a mission of keeping AD patients in their homes longer, if not until the end.

Uniting and working together, we can establish our own Caregiver Resource base. My call for empowerment includes primary caregivers bonding together to support and share information with one another to enhance and facilitate the AD caregiving process. Primary caregivers can form their own groups with co-workers, church members, neighborhood block members, and social groups. They can recruit, interview, train, and hire in-home-caregivers for their own group. Each member in the designated group would be responsible for doing their own due diligence by determining the needs of their patient, and developing a PADCP that is strength-based for themselves and the in-home-caregiver, if one is required. I predict that for many primary caregivers, an in-home-caregiver will be necessary, particularly if you are employed.

Presently, I am working to organize primary caregivers whom I know are caring for their AD patients. We could have shared the cost for the advertisement that I placed seeking a caregiver that ran for four days, and cost \$69. We could have divided up the calls, the advertisement generated, and scheduled a group interview. Each primary caregiver would have the opportunity to interview, assess, and hire the caregiver who fits their needs. For example, a car is desirable for our dad, but may not be required for another patient. Some primary caregivers may only need part-time help, others full-time or live-in, still others, just weekends. The pool of caregivers allows you to do less and accomplish more. Not to mention the sense of camaraderie that can overcome that sense of *I'm all alone* and give you the *caregiver blues* – my old mantra.

It is also our intentions to help *caregivers with a calling* by recruiting and training them in our prototype of quality care for AD patients. As you know, our emphasis is on a strength-based view of thinking, and designing and implementing a PADCP. With mastery of these tools, caregivers will have tangible assets that will be beneficial to novice primary caregivers like we were, and their patients. I would venture to say that they will always be employed. I've always believed that if you sincerely provide a service authentically coupled with skill and knowledge, the money will follow.

It is very satisfying to us that we didn't feed into the hype that it is almost impossible to manage AD in the patient's home or the home of a relative, particularly in the Middle-Late Stages. Many books, articles, reports, and TV shows portray AD patients who display serious behavior problems, such as violence and combativeness, hallucinations, and extreme mania, to name a few. There are, however, a significant number of patients who glide through their AD journey that we rarely hear anything about. Then there are those that we always hear about who go kicking and screaming.

I am very appreciative of the information I received about AD through brochures and books obtained from my local Alzheimer's Association, and in their meetings, workshops, and conferences. The Alzheimer's Association is also a wonderful resource for researching

or locating current research studies and clinical trials on AD that may be of interest to you or your loved one. Further, I attended several retreats given by a local Caregiver Resource Center, in Los Angeles that were very informative and always a source of respite for us weary caregivers. The Mary Easton Center for Alzheimer's Disease Research at UCLA and the University of Southern California Keck School of Medicine and the Memory and Aging Center, have been excellent resources and furnished me with unparalleled additional information on research studies and clinical trials on dementia, as well as knowledge to provide our dad with the quality of care we know he deserves.

There are many clinicians who believe that the stages of AD are not very useful for education or beneficial for planning care because of the extreme variables regarding the onset, the presentation, and the severity of symptoms. But I must say that had I not been aware of the stages of AD, the progression of the disease, and the ups and down of the disease, I would have been totally overwhelmed, hopeless, and probably on the verge of my own nervous breakdown.

For this reason, I urge you to do your homework. This book is a great place to start because the focus is not clinical. Rather, it is an empathetic and personal viewpoint from the perspective of the primary caregiver and the patient. Yet it provides factual information that will assist you in your decision-making.

It is clear to me now that Dad was probably exhibiting AD symptoms approximately two or three years prior to his official diagnosis. Much of the behavior we attributed to grief, most likely were AD symptoms. It is very possible that the loss of our mother in August 2000 and the knee surgery in November 2000 accompanied with general anesthesia escalated the onslaught of the AD symptoms. That's been my suspicion all along, and I'm sticking to it!

Everything noted here is a learning process, and I have learned that Dad's sense of loss is consistent with the progression of the disease, when nothing feels familiar to you – people, your home, even your own face. Although Dad says that he feels lost sometimes, I sense that

he still does have a deep sense of himself and his connection with my brother and me, and that he is comfortable in his home. I have studied books and articles where authors have stated that AD patients lose their souls. Nancy Reagan couldn't have said it better when speaking about her late husband, Ronald Reagan. She said, "His body may have Alzheimer's, but his soul doesn't." I concur with Mrs. Reagan and believe that real caregiving takes place within a relationship. I think AD patients know their loved ones and those who really care about them on a *soul* or *spiritual* level. They know there is a connection. If you really pay attention often you will see a glimpse of *memory* in their eyes of you and other things important to them.

There are people that think the relationship is over as a result of the effects of AD. I personally believe and have experienced with Dad an awareness of a very rich relationship between the two of us. I have observed a similar experience with my brother and Dad. There is no doubt that the relationship has changed. Most of time I don't think he experiences me as his daughter, or my brother as his son. He smiles and is happy to see us most of the time. He thanks us for everything we do with and for him, and he trusts and feels confident about our decisions. Increasingly, I think his experience of us is that we are very kind and loving people whom he is very grateful for as we perform our dutiful tasks in caring for him.

This can be quite disconcerting at first, so let me remind you once more that AD behavior should not be taken personally. The fact that your "loved one" an AD patient may not recognize or remember you as their son, daughter, relative or friend has nothing to do with you, but rather the deterioration of their brain. The word *mommy* or *daddy* may be words many patients like our father no longer understands or remembers. If you recall, earlier I mentioned that after hearing a caregiver give Dad a simple instruction one day, he looked at me and said, they were "just words". Clearly, the words were empty and meaningless to him. But I believe many patients experience the emotions associated with the words – the kind voice, a gentle touch.

Further, I believe that many patients in the very Late and even Terminal stages on occasion recognize themselves and have a sense of connection with others. My girlfriend, whose mother is now 102, believes emphatically that her mother's eyes reflect recognition of herself in a picture when she was very young. (the illustration here: *The 102-Year-Old Patient*) It is for these very reasons that my brother and I decided that regardless of the fatality of this disease, we would not let the disease dictate to us how to care for our dad.



We believe that no matter what the stage of illness a patient is experiencing, they will always respond to a smile and to the gift of love. Do not give up on them because they will feel it and give up as well. Pay attention because you really don't want to miss those glimpses of memory in their eyes! And to think that with the lost memory of who my brother and I really are to him, he still has the wherewithal to thank us for all that we do for him. It warms my heart and we are grateful, and so are the caregivers. On numerous occasions, the live-in-caregivers have told us that Dad expresses heartfelt gratitude to them for their care of him, for which they are so appreciative.

So when these episodes of feeling lost occur, the calm and confident reassurance from my brother and I that we are there for him and *all is well*, appears to reduce his anxiety and sadness. In fact, we often tell him, "Dad we've got you – we're here for you". Most often this soothes him and his mood shifts and a sense of calm returns. Now that we have supportive caregivers who are trained to give the same responses to his sense of loss and other behaviors as well, consistency in our communication is established. Their refrain to Dad's *lost* episodes is, "You're not lost. I am here with you". Finally, we have consistency, a major objective in our PADCP.

I highly suggest that you pay particular attention to the behavioral changes of your loved one upon the aftermath of traumatic experiences such as a recent loss of someone close or role model; loss of a relationship like in a divorce or separation; or loss of a home, job, money, and social status, just to name a few. These may become possible risk factors.

In retrospect, had we been better informed about AD and known what to look for, perhaps an earlier diagnosis after our mother's death could have been more helpful in slowing down the progression of symptoms, or at least managing it better in the beginning. I also believe that guilt is a waste of energy, and when you know better, you do better.

Our dad's internal and external strength and resilience is also the impetus for the writing of this book. I wanted him – this journey

– to be an example to caregivers of an AD patient who successfully remained in his home because of the awareness, knowledge and information acquired by all of the caregivers. I was frustrated with the horrid stories circulating. I wanted to show that finding and hiring good live-in-caregivers who are independent contractors, could be done in a relatively affordable way to accomplish this goal. I believe that many primary caregivers would be able to provide quality live-in-home-care in the AD patient's home at competitive rates, coupled with other incentives, comparable with home health agencies and registries and convalescent homes.

LIFELINES

My suggestions for making in-home-care affordable are a progressive approach and a boon in this economy. Our Assessment Component will assist you in figuring out if you and your patient will be best suited for in-home-care. I am not saying that every *primary caregiver*, be it spouse or adult-child or some other form of personal relation is suited for this challenging job, or that every AD patient can or should remain in the home. I am saying that this is how we did it and made it work for us. Our procedures are designed to guide other novice primary caregivers and the in-home-caregivers as well. Although every AD patient is different, if you can identify one detail in our procedures and start from there, you and the patient will benefit immensely. Keeping an AD patient from being placed in out-of-home-care prematurely is a huge blessing for them, and will be for you. I'm sure most AD patients would agree if they could express themselves lucidly in the latter stages of the disease. It is my intention that readers will benefit from our Edu-illustrations, which are visuals complimented by the narratives we refer to as scenarios, on handling AD behaviors and cognitive changes. The characterizations of the AD patients in the illustrations are primarily based on my father's experiences, except one, *The 102-Year-Old Patient*, which are common challenges to many AD patients and caregivers. The suggestions and recommendations in the Edu-illustrations are actually the interventions and strength-based tools tailored to my

dad's unique situations based on the assessments that determined the development of his PADCP.

I can not reiterate strongly enough that each primary caregiver must design their own PADCP for their patient, based on their patient's personal needs and their familiar environmental needs. In order to do so as a primary caregiver you must first assess whether you are able or ready to be the primary caregiver with or without the assistance of an in-home-care provider. My Assessment Guide will help you make this determination.

Our interviewing suggestions will definitely assist you in differentiating the average caregiver looking for a job from the "*caregiver with a calling*" who is knowledgeable, or at least teachable, in many of the special needs required in caring for AD patients. Hopefully, you will find my suggestions for creative salary negotiations with caregivers insightful and uncanny, to say the least. Ironically, in-home-caregivers also inspired me to write *Stolen*. I found good quality caregivers to be the missing link to a good PADCP for our dad. I really hope that what I've shared resonates with you. If this book inspires caregivers to raise their level of caregiving, then I have achieved my mission.

Stolen was not written to offend or incriminate anyone, but to increase the awareness about a need for compassionate caregivers for this treacherous disease that is exploding in communities the world over. Some caregivers take care of a person on their workday or shift, but caregivers *with a calling* provide a personal service that improves the quality in the way a patient lives. Similar to the way a good teacher is one who has passion for education and teaching, which is inherent to that person. They are their **lifeline**, and in the end, these caregivers will have contributed to a life well-lived.

It is my desire for this book to encourage individuals with "a calling" to receive Specialized Training, in providing care for AD patients. In fact, I believe this training should be mandatory and certified. For those who may not have the "calling," but believe they

can develop the compassion desirable of a quality caregiver, I urge both to pursue training - specifically with the goal to provide care on a level which focuses on being in relationship with the patient; being hands-on and person-centered with the patient; and working from a strength-based view of thinking.

You, are all an AD patient has right now in their pursuit of quality of life, which many progressive sources refer to as meaningful living or enhanced living. Quality care is the sole treatment for an AD patient at a time in which there is currently no cure, and virtually no treatment for this “brain theft” disease.

Equally important, all caregivers need to know that your first responsibility, whether you are a primary caregiver or in-home-caregiver, is to realize the necessity of caring for yourself first in order for you to be “present,” and in relationship with the AD patient. We have always been very concerned about the health and well-being of the caregivers we hire because a person can’t give what they don’t have. If caregivers are anxious, depressed, or troubled, their moods will definitely be conveyed to the patient. If caregivers feel good, have a positive attitude, are calm, patient, and engaging, their moods will affect the patient in a positive way. This pertains to both the primary and the in-home-caregiver as captured in the following words that resonated with me best:

“The more we care for ourselves, it becomes possible to care far more profoundly for other people. The more alert and sensitive we are to our own needs, the more loving and gentle we can be toward others.”

~ Edna LeShan

EYE-OPENERS AND QUESTIONS

As previously mentioned, the medical research field now believes that AD may possibly be dormant in the brain for 10-15 years before

any symptoms become readily apparent. Currently, many research goals center on diagnosing the disease before the symptoms manifest. I've read that a major breakthrough may be occurring for AD in the near future, in approximately 10 or 15 years. My question is, what do we do right now? How do you prevent something when you don't know or understand the origins? And what do the elderly do who are in the throes of AD right now like our dad? What can unsuspecting Baby Boomers do who might already have the benign gluey substance called plaque building up in their brain, causing tangles, as we prepare for our "golden years"?

The initial awareness that aging is considered by many research doctors to be the number one risk factor for getting AD was shocking and left me dumbfounded. Is this what is waiting for us in our golden years? The second risk factor is family history, in other words, genetics, which was more comprehensible to me. Remember those grim statistics that I mentioned earlier? If the numbers are accurate, it is estimated that one in ten people will have some form of dementia or significant memory loss at the age of 65. Then the figures jump to one in two people who will have AD at the age of 85. (Reminder: "Are You At Risk for Alzheimer's" list in Chapter 3, question and answer 2) It is reported that women have AD more than men primarily because women live longer than men. This may be a blessing in disguise to us, as women, because there are also studies that report that men are far more likely than women to leave a seriously ill partner. Nevertheless, I must say that during my AD Journey, I did encounter many men who were primary caregivers and committed to the care of their wives or mother's.

Adult primary caregivers, as well as their younger adult children, should be extremely concerned about our potential risk factors of getting AD simply because we are living longer than our grandparents. For those of us who are Baby Boomers and becoming a little forgetful, and who are already caring for AD patients, we really need to wake up and smell the coffee, as the old saying goes, because of the risks. What we can do right now is make some serious lifestyle changes. Improving our diets, regularly exercising our

body and minds, thinking positive, and getting an early assessment if questionable dementia symptoms occur; are things that we can do for ourselves as well as for our loved ones right now!

We can become pro-active and be conscientious consumers by advocating for healthy and improved diets and making healthier food choices. We can start with taking the time to read the labels on the foods that we choose and purchase wisely. We can select conscientious primary care doctors and clinicians who advocate a low-fat and low-cholesterol diet filled with leafy vegetables and foods high in bioflavonoids and antioxidants, and polyunsaturated fats, and water. Such health-conscience diets may help to reduce the risk of AD, slow the progression of AD, or at the very least, improve a patient's overall general health. There are credible research studies linking a healthy heart with a healthy brain.

It is widely accepted by doctors that diabetes, high blood pressure, and high cholesterol, for many people, are diet-related illnesses. Yes, for some there are genetic links, but even for them, diet is a very important variable. In my course of study about AD, I have learned that there are clinical studies which report people with high blood pressure, high cholesterol, and diabetes have a higher risk for dementias such as AD and Vascular Dementia. Allegedly, this is one of the primary reasons that many doctors think African Americans and Hispanics have a higher risk for these dementias than Caucasians. This was really an eye-opener for me because we are African American. Dad is an African American with AD, and high blood pressure and high cholesterol. The book, *Living in the Moment*, presents some telling information about the effects of stress on a person, and especially their brain. For me, it raised the possibility that persistent, prolonged, severe stress inflicted by situations such as racism could possibly be a link to AD.

Reflecting back on Dad's seven grueling years, as a black man alone in a fire station with overtly racist firemen, I wonder how he suppressed that degree of stress. According to Anna Black, author of *Living in the Moment*, it is a known fact that stress has its way of show-

ing up, no matter how much we suppress it. Further, she contends that long-term stress can result in vulnerability to disease via high blood pressure, risk of diabetes, compromised immune system, and the disruption of memory and thought processes. Ironically, all if not most of these factors are currently linked with AD. As mentioned earlier, when I interviewed Dad in 1994, he attributed his belief and faith in God, and his dream to be a good provider for his family as the factors that got him through his fire station ordeal. I currently believe that my dad may have channeled the stressful negativity of racism on the job in the activity of rigorous exercising at the fire station, and at home. He was known to strenuously work out with weights and do yoga during that period. These are both positive and healthy ways of dealing with stress.

This light-bulb moment has provided me with some insight, though not currently clinical, on how a man with such a healthy lifestyle could still fall victim to AD.

I believe severe stress should also be researched as a viable link for African Americans, Hispanics, and other ethnicities that have experienced severe discrimination and its impact in their daily life experiences. Particularly, since these other ethnicities are projected to have a higher risk for AD than Caucasians, I think it's a credible hypothesis. It is also my understanding that there may be a disparity in the genetic risk factors in African Americans and other ethnicities, compared to Caucasians in the area of AD, which could be another credible reason to clinically research this issue – especially since we know that “chronic stress strengthens negative networks in the brain and weakens positive ones,” according to Anna Black.

Closely related is the latest research linking heart health to brain health since the brain is basically fed and attended to by what an Alzheimer's Association brochure describes as “one of the body's richest networks of blood vessels.” Therefore, if the risk of heart disease, stroke, and diabetes can be reduced by maintaining my blood sugar, cholesterol, blood pressure (stress-related), and weight within the recommended healthy ranges – exercising regularly,

eating a low-fat diet rich with fruits and vegetables, and staying socially and mentally active – overall, all of this may help protect my brain. Wow! That's a big order, but what are my options?

Personally I believe that it is in the early stage of memory loss when there's no or little cognitive impairment that lifestyle intervention in the form of healthy diet, exercise, specific nutrients, may make a difference between relative health and debilitating illnesses such as AD. What if science and research endorse all these lifestyle changes as a deterrent to AD 10 or 15 years from now? Wouldn't you feel cheated if the cure or prevention for AD was linked to diet and healthy lifestyles habits, and you ignored the information? I certainly would!

Be evaluated if you have the slightest suspicion of dementia. If you recall some of the categories in our dad's 2004 MMSE test that I revealed, they should increase your personal awareness. Categories such as: Orientation to place; Recall; Naming objects; Repetition; Comprehension; Reading and Writing are very telling. If you or your loved one find yourself lost going to familiar places; or not recognizing regularly frequented places you're in like: the store, church, your neighbor's home; or you can't recall your address or your best friend's name; or you can't fill out a check properly; you don't understand simple instructions, or there are noticeable repetitions and inability to recall names or familiar information; a noticeable difference in comprehension, reading, and writing – you need to consult with your doctor and request an evaluation.

The question may arise: Why be evaluated and possibly diagnosed with Mild Cognitive Impairment or AD if there's no cure or prevention now? I would answer that early diagnosis could lengthen your life and possibly the quality of your life. All we have currently are a sprinkling of medications like Exelon, Aricept, and Cognex, to name a few, which may slow down the symptoms of AD, and then they level out. However if they are well-tolerated by you, they can make a difference in your quality of life for a period of time.

While researchers, scientists, and doctors are scrambling to find a cure, prevention or even a treatment for AD, we cannot afford to be silent or complacent about this disease. We must read, study, and participate in studies about it. We must dismiss any stigmas that may be associated with AD, talk about it, and help each other to improve our lifestyles. We must stop being in denial or embarrassed about this disease. AD is not a mental illness! It is a disease or illness of the brain - a sickness. It is neurological - not psychiatric. This is why I am persistent about referring to our dad as a *patient*. I am not patronizing him when I refer to him as a *patient*. He is sick, and he has a brain disease!

I advocate that you must listen to and be in touch with your own body. I advocate being in control of our own body and mind and in making informed decisions. Do your own due diligence, read and research the subjects of dementia and AD for your own edification.

CALM IN THE EYE OF A STORM

There is a metaphysical saying that *you teach what you need*. In 2011, I became very concerned about my own memory. There were increasing incidents of *word-finding*, meaning I was unable to readily recall the words I wanted to use in order to express myself. Also, I was unable to immediately recall the names of people I knew. In an effort to follow the advice that I have recommended to others in *Stolen*, I elected to be tested for AD in March of that year. The series of arduous tests revealed that my gross cognitive functioning was fine, as evidenced by a score of 29 out of 30 on the MMSE test. The CDS Inventory Test evaluating depression was good, with a score of 3: indicating no depression.

However, there was an indication of some weakness in the Neuropsychological test. The clinical research diagnosis assigned to me was Mild Cognitive Impairment (MCI). This diagnosis did not include a physical examination, an MRI, or any laboratory work. I referred to MCI earlier in *Stolen* in my brief disclosure about the types of dementias. MCI is a type of dementia. At first I was under

the impression that it is considered a rather gray area where there is a notable difference with memory that could possibly lead to dementia. I have recently learned from credible resources that 50 percent of MCI symptoms escalate to AD symptoms. *Ouch!*

Once I was diagnosed with MCI, it honestly did not cause me any undue concern. This is probably because I had never heard of it before, and the fact that I knew as soon as the testing began that I was in trouble. Mentally I shut down because I wasn't expecting such a grueling testing experience, which felt culturally biased and was projected to last approximately four hours. I didn't understand how many of the questions and answers would inform clinicians about a person's disposition or pre-disposition to dementia, specifically AD.

Previously stated, AD is an equal opportunity disease affecting *all* races, ethnicities, cultures, and economic and educational levels. Diagnosis of the disease should take into consideration all of these factors. The test that were administered to me, did not appear to do so. I am now aware that many researchers are aware of the cultural bias, and those who are empathic believe that research has to start somewhere and believe there is room for improvement later. On the other hand, others simply don't care about the bias, which feels a bit unethical to me.

While taking the test, I started ruminating and wondering how many geriatric parents of Baby Boomers, and for that matter Baby Boomers themselves, would be able to recognize, define, and correctly pronounce the word "hyperbole". By the way, it means excessive, or to exaggerate. In fact, how many of you knew the meaning? And I would love to hear you pronounce it: *hy-per-bo-le*. During the testing I mused, what was the purpose of me reading out loud that word and how relevant was it to diagnosing AD? I have a Master's Degree in Psychology, and am considered intelligent by some people (smile); however, the word *hyperbole* has never been part of my vocabulary or personal experience. Was I educationally deprived?

The interpretation of my answers to the oral and written tests seemed so subjective to me. A few other examples that I recall pondering over were: what if a person had never seen a pyramid and therefore was unable to identify it in this test drawing, would that be a predisposition to AD? Or if a person had never seen a canoe and couldn't distinguish it from a small boat, would that be a predisposition or a sign of dementia or AD? All of these thoughts were going through my head while I was taking the series of tests that day, that were also timed, I might add. I was so anxious and stressed out that the clinicians administering the test allowed me to go to the drug store and purchase medication for a serious headache. This prolonged the test process even further. It took me five hours to complete the series of tests. When I left that day, I was sure my results for these tests and evaluations were going to show major or severe impairment, with a recommendation of institutionalization. Oddly, this was another reason a diagnosis of MCI was acceptable and almost dismissible that day. The following are the results of the tests in the Neuropsychological Assessment Summary Report that I have scanned for the purpose of your edification:

Neuropsychological Laboratory

Name: Lora King
Date of Birth: 12/30/1946
Date of Testing: 3/30/2011
Age at Testing: 64

This report contains information about participants' performances on standardized neuropsychological measures completed for research purposes only. Please note that many individuals have strengths and weaknesses even if they do not have a cognitive disorder.

Ms. Lora King is a 64-year-old, right-handed, African-American female with 18 years of education. She attended an initial visit as a participant for the Easton Center for Alzheimer's Disease Research at UCLA. She reported difficulties with recent memory, word finding, and attention. She stated that she is able to independently perform activities of daily living (ADLs). Gross cognitive functioning was intact (MMSE = 29). A self-report inventory (GDS = 3) and brief interview did not indicate depression.

Neuropsychological test results revealed difficulties in psychomotor sequencing (aspect of processing speed), confrontation naming (aspect of language), verbal memory for structured information, and aspects of executive functioning (novel problem solving and cognitive flexibility). Relative weaknesses were found in semantic fluency (aspect of language), complex visuoconstruction (aspect of visuospatial skills), nonverbal memory for complex material, and aspects of executive functioning (response inhibition and word generation). The following areas were intact for her age, including: simple attention, graphomotor speed (aspect of processing speed), gross visuoconstruction (aspect of visuospatial skills), and aspects of memory (verbal memory for contextually related information and nonverbal memory for simple material).

She currently has difficulties in aspects of processing speed, language, memory and executive functioning. Coupled with reportedly intact ability to complete ADLs, her current research diagnosis is **Mild Cognitive Impairment, amnesic type, multiple domains**.

Psychometrist

Supervising Neuropsychologist

Did you understand this wonderful Neuropsychological Assessment Summary Report? Well neither did I, nor did anyone bother to give me a comprehensive explanation about it. I have shared this personal information with you to increase your awareness about the contents and process in many of the research processes and clinical trials for AD.

Due to my participation in this research project it became almost painfully evident that in order to find a cure or even preventative measures for all AD patients, you and I must realize our obligation to be a part of the process and communicate our concerns. Some of my concerns are objective evaluations, and equally important, objective interpretation of the results, and empathetic communications that I have voiced to the appropriate administrators. A cure, prevention, and treatment of AD are incumbent upon research; and research is based on rigorous clinical trials. Although this testing and evaluation experience was not enjoyable, it was definitely educational. I'm encouraged by the fact that future diagnostic tests will be utilizing more objective tools often used for neuro-imaging of the brain. They will be investigating the development of AD in the aging population using brain-imaging processes similar to Magnetic Resonance Imaging (MRI) and Positron Emission Tomography (PET) scans. Researchers will be looking to study and analyze different types of genes and proteins. Some clinical studies involve studying samples of blood. In my opinion, these types of clinical studies are an improvement to the subjective tests to which I was exposed.

Having said that, it seemed almost indisputable to me that though the tests I took were culturally biased, and I didn't really understand the summary report, I knew I had some memory issues. It was when I noticed regular episodes of forgetfulness and memory gaps that I decided to be evaluated in the first place. Probably if I had not been studying and researching the subject of dementia, specifically AD on our dad's behalf, I would have reverted back to the past practice of relegating my episodes to age, stress, and "senior moments".

But I knew too much about dementia to be in denial now. In other words, *I knew that I know what I know*. I had become very clumsy, disorganized, and was prone to transposing letters in words and numbers, mispronunciations and misspelling of words.

I am now faced with what I call a '*fork in the road*' in my personal life. When I was evaluated and assigned the research diagnosis in March 2011, I was not told that 50 percent of people diagnosed with

MCI eventually get AD symptoms. I was simply told that I would be monitored and annually I would be tested to see if the MCI was progressing. I think I should have been given some suggestions to help myself possibly mitigate the symptoms. But that's not what research is about, is it? To do nothing would be a big mistake. I decided to be proactive and set out to improve my lifestyle, as I recommended to you earlier. I choose life. In fact, I choose a quality life. Therefore, I am exercising, eating healthier foods, staying positive, and continuing to study and research credible data and recommendations and suggestions to mitigate or stop the thievery of AD. I do intend to blog about these activities.

I asked you a question in the beginning of this book, and I'm going to ask the same question at the conclusion – **“How would you want to be cared for if you had AD, and how would you pay for it?”** I am really musing about this question now. I am contemplating healthcare and personal care options important to me should I have to navigate this brain-theft invasion. I've come up with a number of practical ideas I'm researching in case they may be needed. Similar to Dad, I have little to no family resources, so I will probably have to rely on in-home-care services. This is not being negative or pessimistic thinking. This new information has simply heightened my awareness and critical thinking skills. It is my desire that *Stolen* will do the same for you.

My last gentle reminder about this factor is that we had Dad tested for AD when he started to act differently. I learned later that if the patient or the caregiver can identify the loss of memory incidents as possible AD symptoms and have the patient assessed and diagnosed immediately, the progression of the symptoms of the disease could possibly be slowed down with medications. Assessment and diagnosis before the behavior changes manifest is the objective in the Early Stage of AD. I know that to identify early symptoms, possibly of AD, is probably easier said than to do. Many people, similar to me, may not know that they should consult with their doctor when forgetfulness and memory loss become very noticeable to them and by others because of their age. You and your loved one

should be assessed at this time. I know that I was, and I am grateful for making that decision.

CHAPTER 12

WORDS FROM THE EXPERTS



Some readers may think that I've saved the best for last. I'd like to think that this section brings balance to what I've discussed throughout the book. I am very grateful for the wonderful doctors who have penned their opinions that follow, to concerns in *Stolen* which really resonated with me, such as: (1) As primary caregivers, were we making the best decisions on Dad's behalf? (2) Their insight on AD research and clinical trials. (3) My suspicion about surgery involving general anesthesia and the impact on an AD patient.

First, I wanted to lay the foundation about our perspective on AD as a novice primary caregiver. Then I wanted the professionals, who are all specialists in their specific fields, to weigh-in after I finished writing our chronology of our experiences. The following are the excerpts from:

- Sonia Pawluczyk, M.D.
- Joshua Grill, PhD
- Julia Ray, M.D./Anesthesiologist

MY CONVERSATIONS WITH “DR. P”

Our journey to get Dad the best care led us to Sonia Pawluczyk, M.D., Assistant Professor of Clinical Psychiatry and Behavioral Science, Keck School of Medicine; and USC Department of Psychiatry, Geriatric Studies Clinic. Dad’s AD evaluation, formerly referenced to in March 2011, was conducted under the supervision of Dr. Pawluczyk. That day her candid yet compassionate style impressed me.

On March 1, 2012 Dr. Pawluczyk, whom I now affectionately refer to as Dr. “P,” granted me an interview. My purpose for requesting the meeting with her was to clarify some of the issues that were still nagging me about AD, some of which I earlier noted in the section of the book, called “Eye-Openers and Questions.”

I remember feeling a sigh of relief when I told her about our decision not to tell Dad he had AD. She agreed with us that we shouldn’t try to give Dad too much detail about the disease by trying to explain AD to him. She warned us to never tell Dad that he had a severe memory loss or that his memory was getting really bad. She supported us telling him that nothing else was really wrong with him, and reassuring Dad that he was doing well and things were fine otherwise.

Dr. P advocates that we must be careful and empathetic about how we communicate about AD to a patient. She urges caregivers to be conscious of the language we use to describe their condition to them. In fact, she vehemently declares that caregivers, similar to all physicians, should “*do no harm*” to patients. Although she may tell the primary caregiver(s) that the patient has severe memory loss; her choice of words to the patient is considerably different. She may say your memory may be changing or you may be experiencing some difficulty recalling things that may be related to normal aging. Dr. P advised me that as a primary caregiver, you never want to make the patient feel bad by saying you definitely have a problem or you have dementia. Oops, I thought!

She went on to share that as a psychiatrist often working with demented patients, she has observed that some people are so fearful of the disease that some say they would consider suicide rather than navigate through the AD process. However, these same people

find it more doable and comforting when she refers to the disease as *memory loss*. This really confirmed what we had observed with our dad when he asked, “What is wrong with me?” or “What is happening to me?” Now we would calmly tell him that his memory may be changing due to his age and this definitely seems to pacify him more. We no longer tell Dad that he has a serious memory problem because of the harmful impact it may have on him.

When I shared Dad’s feelings of being lost sometimes, Dr. P inquired whether we thought Dad was depressed. She agreed with me that the intermittent episodes of feeling lost lacked the persistency of episodes symptomatic of depression. She did, however, suggest that Dad might be having feelings that he was unable to express, like probing questions about death and dying. She suggested that if we felt comfortable enough, we should give him the opportunity to talk about it, if that’s what he wants to talk about. She suggested asking him something like, “Do you feel like something bad is going to happen?” I decided that I would feel comfortable with this line of questioning if and when the next episode of *lost* occurred.

Dr. P told me that our job as the primary caregivers is to “protect” our father. She said that we must have a joyful spirit because we are our father’s conduit to a failing world which is becoming more blurred daily. We need to validate his emotions, encourage him with a positive attitude, and praise him instead of asking questions that he can’t answer. And most importantly, we have to stop looking at him sadly because he can’t remember or recognize formerly familiar things and people such as his home or the faces of his children and grandchildren.

We protect him by ignoring memory failures such as this and by redirecting the conversation. Dr. P validated our efforts to hire in-home-caregivers that shadow the same good caregiver that my brother and I are trying to be. She emphasized that all of us must protect Dad by letting him know that he is not lost and that we are here for him. We all must continue to tell him that he is in his 90’s and his memory is just fading.

“Ignorance is Not Bliss” is another section here in *Stolen* that opened up a whirlwind of thoughts and unanswered questions. In our conversation that day, Dr. P reminded me that in reality, the more you know, actually the less you know. This oxymoron really

spoke to me. Although there's an abundance of information available on dementia and AD, there's so much that doctors, clinicians, and researchers don't know about the etiology of AD. Information is constantly evolving.

The same way I recommended that we allow AD patients to live in the "now," meaning their world, I had temporarily forgotten to live *in the here and now* in my own life. I had begun to lose the awareness of the gifts and blessings I have now because I started ruminating about the possibility of me having or getting AD in the not too distant future because of the clinical diagnosis of Mild Cognitive Impairment (MCI). Although there were extensive neuropsychological tests and evaluations administered in order to make this diagnosis, Dr. P cautioned me not to be alarmed.

She informed me that the initial diagnosis I was given for MCI doesn't really have a great deal of meaning until the clinicians are able to see if there are any changes once they compare this evaluation to the next one I will take. She said it could have been a bad day or I could have been sick the day of the evaluation and this would have definitely affected my performance.

I snickered a bit to myself, because as I disclosed earlier, my performance went downhill as soon as the test began because of the unanticipated bias in the tests. Dr. P reminded me that there are clearly normal age related memory losses, which may be difficult to distinguish from dementia. She also acknowledged that there is some bias in the tests for ethnic groups as well as some bias for women.

I shared with Dr. P that I wish the clinicians administering the tests and the test results would be more compassionate in their delivery and more communicative about what the results of the tests mean. She explained that often a study involves research for something specific. When and if they find *it* in their specific study, often they really don't know what it means because they are uncertain of the clinical implications at that time. Consequently, they really don't know what to tell a subject when that happens. Clearly, I was naïve about the research process. Frankly, I was anticipating some type of concrete feedback about the results, which could be beneficial to me personally. I am now more altruistic about my research endeavors.

Dr. P advised that instead of worrying and focusing on how we can prevent getting AD, we should focus primarily on doing what's best for our body. And what's good for the heart is also good for the brain, she reiterated. She stressed that it is through the donation of our brains, primarily for the autopsy process, that a cure will be found because they have to find out what is going on in the brain.

When I inquired about Dr. P's opinion on the explosion of studies to find a cure, to prevent, and to treat the disease, she warned that doctors and researchers have to be very careful about their statements in reporting conclusive results in these studies. In reality, for a cure to be found, it will only be done through clinical trials involving large populations, which she referred to as "studies with scientific rigor." Not only will these studies for a cure have to involve thousands and thousands of people, but the results must be the same and consistent each time. This reminded me of my concern that for it to be a cure for everyone – all ethnicities – we must take some ownership in finding a cure by personally getting involved in clinical and research studies. Need I remind you again, AD is an equal opportunity thief!

She encouraged me to continue in the study to see if there are changes in my memory from year to year. She shared that there are individuals who have been subjects for some of their studies and clinical trials for eight to ten years. She also enlightened me about the purpose of the "informants." In the current study that I am participating in, they refer to them as study partners. Basically the informants, a.k.a. study partners, are considered to be the objective observers of the subject, a.k.a. participant or volunteer partners, in the study. They should be someone close to you and someone who knows you well.

They are expected to accompany the volunteer subject to all the clinic visits. They are expected to communicate any changes they have observed during the reporting period. For example, are there regular episodes of forgetting to pay bills; or is the house unusually disorganized and unkempt; or perhaps, there is no change during a reporting period. Thanks to Dr. P, I'll look forward to continuing my annual evaluation sessions with one my best friends.

When I walked into Dr. P's office on that fateful day, March 1, 2012, I felt a heaviness and weight on my shoulders. I actually felt

anxious and resigned to a fate of AD in the future. When I left that day after our two-hour interview, I walked out feeling lighter, like a weight had been lifted off of me, and hopeful. In fact, a day later, I even felt invigorated again.

Even though Dad's sad experiences and struggles with the progression of AD were juxtaposed with positive and amusing experiences, I thought the experience of writing *Stolen* was going to be liberating, not anguished. I was not expecting the profound impact that I was feeling. Dr. P helped me get back in touch with myself in her professional yet unassuming manner. As a result of our conversation, I am currently enthusiastic about choosing to change my lifestyle by incorporating regular exercise and eating mindfully – not because of the MCI diagnosis, but for my overall health and well-being. Ironically, this has always been an important objective in Dad's Personal Alzheimer's Disease Care Plan (PADCP). Now I am making it an important objective in my personal care plan. I obviously need to practice and value myself more by doing for myself what I advocate for our dad and to others.

Note: MCI is not considered a clinical diagnosis-it is a research diagnosis, and often referred to as possibly a statement of AD.

A Primer on Alzheimer's Disease

by Joshua D. Grill, PhD

AD 101

More than five million Americans have Alzheimer's Disease. Most AD patients are over the age of 65 and age is the greatest risk factor for getting AD. For every five years a person lives after the age of 60, the risk for getting AD doubles.

The elderly are among the fastest growing segments of the U.S. and world populations. According to the Census Bureau, between 2000 and 2010, there was a 31 percent increase in the number of people between ages 45 and 64 and a 15 percent increase in persons 65 or older in the U.S. Thus, the number of people living to the ages at greatest risk for AD has and will continue to rapidly increase and a tidal wave of elderly Americans will soon be upon us. Of particular importance is the Baby Boom generation – those born between 1946 and 1964. The first boomers turned 65 in 2011 and more than 10 million are expected to get AD. In fact, it is expected that by 2050, the total number of people with AD will reach 12-16 million in this country.

The associated healthcare cost of AD in the U.S. was more than \$180 billion in 2010. Once the Baby Boomers have all reached the ages at risk for AD, this could skyrocket to \$1 trillion. AD, by itself, could bankrupt the U.S. healthcare system.

AD is a progressive neurodegenerative disease. Dr. Alois Alzheimer, a Bavarian physician, first characterized it. He noted peculiar behaviors, including memory loss, in his patient *August D.* and followed her clinically for the rest of her life. AD is not a normal part of aging (not everyone who gets older gets AD). Once AD begins, it is unrelenting – robbing patients of their cognitive (or thinking) and functional (daily activities) abilities and increasing in severity over time.

Cognitive abilities come in many forms. The clinical hallmark of AD is short-term memory impairment. There are other forms of cognition, however, including language (both the ability to produce it and understand it), orientation (i.e. know who we are, where we

are), and executive function (being able to plan and make decisions, knowing right from wrong). AD is only diagnosed when two distinct forms of cognition have become impaired (one of them being memory) and when those impairments get in the way of how one lives their life. That is when one has dementia.

The terms *dementia* and *Alzheimer's* are often used interchangeably (other terms include *senile dementia* and *senility*). In fact, dementia refers to the clinical syndrome in which two domains of thinking ability have worsened and it prevents a person from living life the way they did before they got sick. There are many causes of dementia. Some are reversible, like some vitamin deficiencies or hormone imbalances, but most are not. AD is the cause of 60 to 70 percent of all cases of dementia and is irreversible.

When August D. died, Dr. Alzheimer examined her brain and found two abnormalities. Though it was more than 100 years ago, we continue to study those two abnormalities today. They are called **plaques** (or amyloid plaques or senile plaques) and **tangles** (or neurofibrillary tangles). Plaques are accumulations between nerve cells (neurons) of a sticky protein called beta amyloid. They seem to interrupt the connections between nerve cells called synapses.

Synapses are the basic unit of brain function. Synapses give us the ability to think, make new memories and recall them, and feel emotions. They also ensure that we eat, breathe, and do all basic biological activities. The plaques seem to disrupt synapses and choke nerve cells. As a result, neurons and synapses are lost (or degenerate) because of the disease. Once a cell is destined to be lost, it may take a fair amount of time before it dies. At some point in that process, inside a nerve cell, tangles will form. Tangles cause malfunctioning of a nerve cell's internal machinery.

As synapses and nerve cells are lost, the thinking skills of people with AD are similarly lost. As thinking skills worsen, so do the abilities to perform even our most basic activities. Functional problems may first be observed with more complex things like balancing a checkbook or paying the bills. Eventually, things like using the washer/dryer or dishwasher, telephone, and other even more simple functions like eating and going to the bathroom will decline and be lost.

As you have read in *Stolen*, the cognitive and functional impairments that occur in AD patients place a tremendous mental and physical burden on loved ones who must ensure safety and provide care.

But not everyone who lives to be in their 60's, 70's, and 80's gets AD, only a fraction do. Why do some older people get the disease and others not? This is an important question and an area of intense research. Genes play a role in AD risk. Those with a parent who had AD are at slightly increased risk compared to someone who did not. Still, not everyone who had a parent with AD will get it, and not everyone who gets AD has a parent who had it. Several genes seem to increase risk, but none are predictive or diagnostic. There are some very rare genetic mutations that can cause AD, but they account for less than two percent of all cases, have a very young age of onset (in the 30's, 40's, or 50's) and won't be discussed further here.

Some medical conditions such as diabetes, hypertension (high blood pressure), hypercholesterolemia (high cholesterol), and head injuries can increase risk for AD. Alternatively, eating a healthy diet with enough fish, fruits, and vegetables and getting the recommended amounts of exercise may lower risk for AD. Staying mentally and socially active also may lower risk.

AD knows no cultural or ethnic bounds. Every population worldwide that lives to be old enough is at risk for AD. In this country, a variety of studies suggest that African Americans and Latinos are at increased risk for AD, relative to non-Latino Caucasians. Understanding AD in African Americans and Latinos is in need of further study. Many of the risk factors listed above, like diabetes and hypertension, are more common in the African-American and Latino communities. This could explain increased risk. Other studies, however, suggest some of the genetic risk factors for AD work differently or not at all in African Americans and Latinos.

The fact of the matter is that we just do not yet know if AD is the same in the different races and ethnicities. The only way to understand if AD is different among different populations and to find better treatments for all people with dementia is through research.

AD Research

Research is systematic study to learn facts and enhance understanding. We do research in AD to get better at diagnosing, providing care, and treating the disease. Without research, there will be no cure or prevention for AD.

We do research because we want to help as many patients with AD as possible, so we study a few (sometimes a *few* means a thousand or more), in hopes of learning about *all* patients.

Research is highly regulated. As researchers, we take it upon ourselves to make participant safety the highest priority. To help ensure participant safety, there are many other precautions put in place. Research is regulated federally by the National Institutes of Health (NIH, which funds the majority of U.S. research studies) and the Food and Drug Administration (FDA, which decides what drugs can be used and which may not) and locally, by Institutional Review Boards (IRB; local organizations that oversee research conduct to ensure participant safety), and other committees. Clinicians and scientists must have extensive training and must maintain certifications to conduct research.

Many laws and regulations related to research are in place because of past problems with the ways that research was conducted. Atrocities like the Tuskegee Syphilis Experiment (in which African-American men who already had syphilis and were being followed as part of a study were not offered treatment when it became available) and the case of Henrietta Leaks (an African-American woman whose cancer cells were collected for research purposes without her consent or knowledge, as is described in the remarkable book *The Immortal Life of Henrietta Leaks*, by Rebecca Skloot) cannot be forgotten, nor should they be pushed aside and pretended to have not happened. They also, however, cannot be allowed to deter medical progress for all people.

Even though there are many precautionary checks in place to ensure safety, anyone considering research participation should make the decision carefully. The person conducting the research should 1) make you feel comfortable and confident that your safety is priority, 2) communicate the goals of the research and those goals

should be important to you, and 3) make it clear that you are a volunteer, free to choose to not participate or to withdraw your participation at any time. This should all be done in person and in writing, with a document called an *informed consent*.

Research participation can vary substantially. We conduct some studies in which we ask participants to give one hour of their time completing a survey. More frequently, we invite participants to undergo clinical evaluations on an annual basis so that we may study how cognition changes with age in those who do and do not have disease. Other times, we ask participants to undergo blood tests or brain scans.

In probably our most involved type of research, we invite those who have been diagnosed with AD to participate in clinical trials of new medications that last years, require many visits, and carry several risks. These research studies involve extra visits to the doctor, pencil and paper memory and thinking tests, blood tests, and brain scans. Some involve undergoing procedures like spinal taps.

In most clinical research studies, we also invite participants to consider donating their brain to research that involves autopsy. This can be done with great sensitivity and within nearly any religious belief system. Autopsy research is responsible for some of the greatest advancements in understanding AD to date, beginning first with August D. and Dr. Alzheimer, and including a large number of recent studies that have pushed the field toward better understanding and improved therapies.

The reality is that every new diagnostic test, every risk-lowering strategy and recommendation, and every vaccination we give our children and drug we take had to go through the same clinical research development process. The process is rigorous, difficult, expensive, and highly regulated. And in essentially every case, one of the main barriers to having new treatments and tools in the clinic is getting enough people to participate in research studies.

Progress in AD

According to the Alzheimer's Association, between 2000 and 2008, the number of U.S. deaths caused by stroke decreased 20

percent. Deaths caused by prostate cancer went down eight percent. Breast cancer deaths declined three percent. Heart disease related death went down 13 percent. Death caused by HIV/AIDS went down 29 percent. In that same period of time, ***the number of deaths caused by AD increased by 66 percent.***

The increase was likely caused by improved recognition of AD and the earlier discussed increases in the number of people living to the ages at risk for AD. But Dr. Alzheimer described the disease more than a hundred years ago. Why isn't medicine making the same strides in AD as are seen in other areas?

First, AD may represent a tougher nut to crack than some of those other conditions. Even the healthy brain remains, to some extent, a mystery. Fully understanding the unhealthy brain means additional challenges. Despite this, in those 100 years, we have learned a lot about AD and about plaques and tangles.

There are now two classes of medications approved by the FDA for the treatment of AD. Both classes are considered *symptomatic* treatments; they help patients perform a little better on memory and thinking tests. The medications target chemicals made by brain cells, but don't have any impact on the loss of synapses or cells that most researchers believe will be key to stopping AD. The field is now very focused on finding *disease-modifying therapies*, drugs that can actually slow the course of AD. These drugs will target the underlying biology of the disease.

Disease-modifying therapies will be important for several reasons. First, with drugs that can slow AD, we can give patients longer periods of time with greater cognitive function. Second, it has become increasingly clear that AD is a long process. Clinical symptoms can last 10-15 years, but even this may be preceded by a period of biological buildup that begins 10 years before the diagnosis of dementia – this shows how amazing the brain is, that it can stave off symptoms for a decade despite the presence of disease. This long silent period also may introduce the opportunity to identify persons in whom disease is present and allow the initiation of disease-slowing therapy that prevents them from ever getting dementia. If a drug can delay the onset of dementia by five years, it would reduce the total number of cases by 50 percent.

Several candidate disease-modifying therapies are in development for AD. Many are even in clinical trials and some have been shown to actually reduce the plaques in AD patients' brains. It is indeed an exciting time in AD research.

Perhaps more than for any other type of research, clinical trials faces significant barriers to enrolling participants. First, clinical trials are designed very carefully and only a fraction of AD patients will be eligible to participate. This is done to ensure the safety of those who enroll. Most AD patients and their families are not aware of AD trials.

National websites like www.clinicaltrials.gov are now available so that any person who wants to learn about any clinical trials for any medical condition in this country can do so. There are also national websites supported by the National Institute on Aging, which is the NIH institute that funds most AD research (<http://www.nia.nih.gov/Alzheimers/>). Last year, the government started a new website (www.alzheimers.gov) for caregivers and the general public that includes detailed information about local resources. Finally, centers like ours at UCLA maintain websites so that patients and families have local resources as well (www.EastonAD.ucla.edu).

Summary

In conclusion, AD is perhaps the most important medical challenge today. An extremely large number of people are afflicted with AD and this will increase significantly in the near future. The AD epidemic will affect us all. Everyone who gets older is at risk and AD may bankrupt the national healthcare system. Research has made tremendous strides in understanding who is at greatest risk for AD; what happens in the brain of someone with AD and when these events begin; and how we may try to slow, stop, or reverse the biological changes of this disease. Research will be key to staving off the outcomes discussed, but researchers need help.

When people ask me what they can do to help, I often refer to the three “-ates.” People can participate, donate, and advocate. Research progress is entirely dependent upon volunteers who agree to give their time and effort to be part of studies. Participation can

vary in the amount of time, effort, or the level of medical procedures involved. One thing that is consistent across all clinical research studies, however, is the fact that if people don't volunteer to participate, those studies will fail and our pursuit of a cure will be delayed.

For perhaps a select few, providing financial donations for AD research or AD care programs is a way to support AD without participating in studies. Generous donors may give to research centers like ours or to organizations that fund research, like the John Douglas French Foundation or the AD Drug Discovery Foundation. Alternatively, community organizations like the Leeza Gibbons Memory Foundation, the Alzheimer's Foundation of America, and the Alzheimer's Association provide invaluable resources for families with AD and are always in need of fiscal assistance.

Research is underfunded and with more dollars we could do more, faster. But not everyone can afford to give his or her own money. Everyone can, however, call their federal or state representative and tell them that AD is going to bankrupt our country if we don't find a prevention soon and that there needs to be greater research funding. Tell them also that families dealing with this disease need more government support in the form of services and financial assistance. In 2012, the Obama Administration released the National Alzheimer's Plan, which budgeted \$80 million for research and \$20 million for caregiver support and education. While this is an important step, it is not enough. Some suggest that a billion dollar investment will be necessary to meet the National Alzheimer's Plan's primary objective: to have disease-preventing treatments by 2025.

This is an exciting time in AD research. The field is advancing at a rapid rate, learning more about the molecular, cellular, and clinical manifestations of the disease, and continually making important strides toward improved treatments and eventual prevention. But only working together as a highly collaborative team of research scientists, government officials, industry partners, and patient volunteers and families will we reach our singular goal of defeating AD.

ANESTHESIA AND ALZHEIMER'S DISEASE

By Julia Ray M.D./Anesthesiologist

How plausible is it to speculate, as Lora King has, that it was the anesthesia that had an effect on the subject (Wince King) with Alzheimer's Disease? The short answer is – very plausible. Some patients and their families can even time the onset of symptoms of their AD from a particular surgical procedure. Scientists have recently begun studying the effects of the phenomenon and have even coined the term *Post Operative Cognitive Decline (POCD)* to describe the decline in cognitive brain function that can last in older subjects for days, and even as long as 12 weeks, post-operatively.

While current anesthesia has become a lot safer in many ways on the heart, kidneys and other vital organs, the problems with anesthesia on the brain are now recently of great concern in light of greater awareness of POCD.

As scientists research the problem of POCD, studies have suggested that it is not only the anesthesia (which renders an unconscious state to pain and memory), but it actually can be the mere act of surgery itself.

Science Daily, in its September 2012 issue, reports that “surgery itself has a more profound effect than does anesthesia on the brain pathology of cognition.”

And the *ANNALS OF SURGERY* in their animal model studies, have reported that, at least in the rat model, it is the surgery itself rather than the anesthesia that has a more profound effect on the dementia.

The mechanism linking surgery and the cognitive effects appear to be an inflammatory process. While it is widely accepted that there is an inflammatory process that occurs post-operatively, how this inflammatory process gains access to the brain and accelerates AD pathology in a persistent way is still unclear.

So Lora King is right to question her observation and to be assertive as an advocate for clinical trial participation. It is through research that we can better find answers to the many questions that remain mysteries to us doctors and laymen alike.

What is clear is that there is a need to further research the POCD syndrome and that there is hope that the inflammatory process as the underlying mechanism suggests a strategy for mitigating injury. Human studies will be needed to first confirm these findings and then begin to deploy anti-inflammatory strategies to minimize injury.

In conclusion, as a profession, doctors need to understand the long-term implications of AD and do all we can to delay the onset of dementia.

CHAPTER 13

THE PROMISE



My brother and I remain fervent about keeping Dad in his home for as long as humanly and humanely possible. The caveat for me is the Terminal Stage of AD. This is basically the end of life stage. This in itself is difficult to face because of the finality of a loved one's earthly demise. No matter how prepared you are intellectually, death still catches us off guard. We have been determined to advocate for quality care for our dad even when it often appears that the medical field has marginalized his life and given up on him because of his age.

Whether Dad's cycle for this disease is short or long, our goal was and remains quality care to the end. However, if Dad has multiple chronic illnesses or severe medical issues that require specialized medical equipment and a medically trained staff not available for in-home services, I realize that he may not be able to remain in his home. My first choice would be to investigate the feasibility of a residential home for AD patients, staffed with caregivers trained in providing specialized care for the elderly with dementia, and able to accommodate the medical equipment required. My last choice would be a skilled nursing home or convalescent home with a day nurse if Dad had medical conditions that could not be accommodated in a home environment. At this point, removing him from his home whether in a conscious or unconscious state would be the last possession stolen from him.

My brother and I have been on our journey to keep our dad in his home for over a decade. Even though we know AD is a dead-end road, we are determined to provide quality care to Dad with the assistance of in-home-caregivers while on this road.

The journey has taken us on a variety of unsuspecting twists and turns leading us down different roads:

- a road that led to an assessment of quality care resulting in me redefining it due to the impact of AD on patients;
- a road that led to a look at the definition of dementia and how AD is a type of dementia and can have some similar symptoms to other ones;
- a road that led to in-home-care and registries, agencies, and independent caregivers who contract for direct pay;
- a road that detoured and led to a look at caregivers with a calling and those simply looking for a job, and how to determine the difference;
- a fork in the road that made me decide to advocate on behalf of AD patients and recommend that in-home-caregivers need to raise the bar and provide better quality care to their patients because of their invaluable contribution to the patient's sense of well-being and quality of life;
- to a bumpy road on issues of autopsies, end of life, and hospice care;
- to a foggy road on testing and evaluating AD patients and the impact of research studies and clinical trials on finding a cure for AD;
- to better vision and direction on the road by designing a Personal Alzheimer's Disease Care Plan (PADCP) and the corresponding assessment components;
- to a cul-de-sac consisting of out-of-care facilities such as convalescent and nursing homes, assisted living, and residential group homes;
- and lastly to a gravel road of how to pay for quality care.

I must say I'd be remiss if I didn't include this book, this gift, as a path I veered off onto on this journey that has led me to you. All this and more of our journey has been shared with you in order to enhance your awareness about this disease, and to help you make an informed decision, if and when it becomes necessary.

Finally, the "good news" is that we have encountered some wonderful role models of primary caregivers in our journey. They are currently providing or have provided quality care to their loved ones in their own home or the home of the relative, with the assistance of affordable in-home-care-providers, to the ripe ages of 90 and even the 100's. That is our goal, too, and the promise my brother and I made to each other. However, a picture is worth a thousand words. The following is my first **blog** commentary, to be found at: <http://stolenbyldk.com/lets-talk/>, and a picture of our Dad age 93 years old:

On December 12, 2012, the black firemen and associates my father served with converged at Dad's home for their 62nd Annual Christmas Party. My brother, a retired fire captain, has hosted this celebration for the last 12 years. It is currently funded by the Stentorians Organization. There are no lay-women at the event, except the caregiver on duty for Dad. "No women present" has been the tradition since the beginning in 1948. Approximately 70 men attended.

A photographer who attended took this picture. My brother posted it on his Facebook page and emailed it to me on Christmas Eve. What a wonderful Christmas gift! The picture took my breath away because of Dad's smiling face, which reflected the joyful spirit he embodies most of the time. Also, I was immediately aware of the personal hygiene and grooming provided by our live-in-caregiver on duty that day. Look at Dad's even, smooth complexion and glowing skin tone. I thought he looked simply great and as does my brother along side of him.

The Los Angeles City Fire Department members presented our dad and family a Certificate of Appreciation for a continued tradition of pride and professionalism in hosting the Christmas Party in his home for 62 years.

I was told that Dad had a wonderful time that evening. He was eating, socializing, shaking hands, and taking individual pictures with the firemen. He retired around 2 a.m.



Picture of the first Black Firemen's Party held in Dad's house in 1950. Dad is the first man, bottom row, left side.



Afterword

DAD'S CAP



Dad adamantly believed in the commandment to “Honor the Sabbath.” He and my mother went to church every Sunday. Even when they were traveling in foreign countries and couldn’t understand the language, they went to church. In trying to keep Dad’s life as constant and consistent as it was before the onset of AD, taking him to church was a personal obligation to me.

As AD progressed, Dad would often get a bit fidgety or take little naps during the sermon. However, I still thought that he benefited spiritually from the service. One day a parishioner stopped and told me that she had observed how Dad always took off his cap as soon as he entered the church door. Even while navigating the walker he used, he would stop abruptly and remove his cap.

I could only hypothesize that this was the result of his childhood upbringing and was still a habit that remained constant with him. Surprisingly, one Sunday in 2011 we walked into church and Dad proceeded to his seat without removing his cap. That moment saddened me because I immediately knew that AD had finally *stolen* this gentile habit of our dad, which was yet another one of his life-long practices, like blessing his food. In denial a bit and not wanting to jump to conclusions, I decided to postpone my initial judgment and observed him a couple of more Sundays. Dad now walks into

church, down the aisle, and sits down with his cap on every Sunday. The gentleman that he still is, he removes his cap when told.

APPENDICES

APPENDIX A

TEST



You've taken the following quiz already by checking either the T (true) or F (false) answer to the questions one through twelve and saved your answers. Now take the quiz again and compare your answers. The correct answers follow.

AD "POP QUIZ"

1. "Love is enough" in providing quality care for AD patients ____T/F____
2. AD is a form of dementia. ____T/F____
3. Telling the AD patient the truth about their illness is the best principle for managing AD behavior. ____T/F____
4. AD is reversible. ____T/F____
5. Most paid or independent caregivers are educated and trained to provide quality care to AD patients. ____T/F____
6. It is always appropriate to give a paid-caregiver a two-week termination notice. ____T/F____
7. Sexual harassment is a valid allegation for sexually inappropriate statements or actions of AD patients. ____T/F____
8. Caregivers should not try to question, reason, or chastise AD patients, if necessary, about their behaviors. ____T/F____
9. Normal aging involves a serious decline in mood, cognition, and functional behavior. ____T/F____

10. To have to stop driving is reportedly one of the most threatening activities related to loss of independence to an AD patient.
___T/F___
11. Sundowning is a natural progression of AD for all patients.
___T/F___
12. Most paid caregivers report that caregiving was their first career option. ___T/F___

TEST ANSWERS

The answers may be very revealing to you. You may see as you compare the first test results to the second how much you have learned and retained.

AD “POP QUIZ”

1. *“Love is enough” in providing quality care for AD patients* (False—pgs. xxv, 73)
2. *AD is a form of dementia.* (True—pg. 30)
3. *Telling the AD patient the truth about their illness is the best principle for managing AD behavior* (False—pgs. 109, 212-213)
4. *AD is reversible.* (False—pg. -34, 37-38)
5. *Most paid or independent caregivers are educated and trained to provide quality care to AD patients.* (False—pgs. 72, 49-50, 160-161, 198-199)
6. *It is always appropriate to give a paid-caregiver a two-week termination notice.* (False—pg. 246)
7. *Sexual harassment is not a valid allegation for sexually inappropriate statements or actions of AD patients.* (True—pgs. 163-165)
8. *Caregivers should not try to question, reason, or chastise AD patients, if necessary, about their behaviors.* (True—pgs. 51, 96, 157, 160, 172)
9. *Normal aging involves a serious decline in mood, cognition, and functional behavior.* (False—pgs. xx, 217-219)
10. *To have to stop driving is reportedly one of the most threatening activities related to loss of independence to an AD patient.* (True—pgs. 87-88, 171)
11. *Sundowning is a natural progression of AD for all patients.* (False—pg. 140-141)
12. *Most paid caregivers report that caregiving was their first career option.* (False—pgs. 125-128, 146)

APPENDIX: B

CAREGIVER PROFILE FOR ALZHEIMER'S PATIENTS



- Joyful spirit
- Self-respect (because without it they can't respect the patient)
- Knowledgeable about the dynamics of AD
- Treats patients with dignity and respect
- Encourages independence
- Has a good sense of humor
- Espouses hope
- Is creative and thinks out of the box
- Takes pride in their work
- Is receptive to suggestions and training
- Is mentally and emotionally stable
- Has a strong sense of work and personal ethics
- Physically healthy and drug free
- Creates a stimulating environment
- Advocates on behalf of the patient

APPENDIX: C

FAMILY STRENGTH ASSESSMENT TOOL



The category of family strengths requires an honest assessment as to whether your family is close (8-10 good), casual 4-7 (average), or estranged (0-3 poor):

A close family relationship is loosely described as a mutually good relationship evidenced by frequent communication, whether physically, verbally, or even via written correspondence. There are basic elements of trust and integrity.

A casual family relationship lacks consistency. There may be little to no trust elements involved in the relationship, probably due to irregularity, unreliability, and because overall, the relationship just lacks heart. However, a casual relationship can become a close one if a need exists and there is commitment from the patient and the caregiver.

An estranged family relationship is generally riddled with discord, antagonism, and often hostility and resentment. The element of trust has been breached. It would take a great deal of work to turn an estranged relationship into a close one in order for the patient to feel secure about receiving quality care and confidence that the family member(s) is committed to providing compassionate care.

Some of the prevalent factors that could be problematic in family relationships when considering a caregiver role that should be assessed and discussed when weighing quality care for an AD patient are:

- Drug and alcohol abuse problems
- Past history of a harmful or tumultuous relationship
- Mentally or emotionally unstable
- Inability to provide patient with consistent physical needs
- Has serious medical condition(s) of their own
- Lacks skills consistent with patient's PADCP and there is no secondary caregiver
- A criminal record
- In it for the money/just a job attitude

REMEMBER > These factors, if unresolved, could have a negative impact on the trust factor, which is a key element in the family strengths assessment, especially when finances are involved.

APPENDIX: D

SAMPLE INTERVIEW QUESTIONS



1. How would you describe yourself, your personality, and your job history?
2. Have you worked with AD patients before and where?
3. Have you ever been a live-in (24-hour) caregiver?
4. Ask as a caregiver, have you ever had a job involving a 12-hour or 24-hour shift change?
5. Will you provide or require a live-scan as a condition for employment?
6. Do you smoke cigarettes?
7. Do you have a car? If so, do you have a valid driver's license and auto insurance?
8. What type of meals do you prepare for yourself? Where do you shop? Do you enjoy cooking?
9. Do you watch TV a lot? What are your favorite programs?

10. Do you know what the term “sundowning” means? Explain in your words.
11. How would you handle sexual statements or advancements from an AD patient?
12. Ask the caregiver if they have ever worked with a patient of the opposite sex. If so, ask if they were comfortable with activities such as dressing, bathing, and incontinence.
13. Ask if they have a checking account or a means of cashing personal checks.
14. Do you have any hospital scrubs? Do you mind wearing them on the job?
15. Do you have a recent TB clearance report? Have you had a CPR class and do you have a current CPR certification?
16. If a caregiver’s cultural background is unclear to you, ask them about it. If you are concerned about their ability to understand and follow your Personal Alzheimer’s Disease Care Plan (Do not ask about their race or ethnicity because this is illegal)

APPENDIX: E

IN-HOME-CARE AGREEMENT



I _____, AS AN INDEPENDENT CONTRACTOR, WILL PROVIDE IN-HOME-CARE FOR _____, "HOMEOWNER," IN HIS RESIDENCE LOCATED AT THE ADDRESS OF _____

I HAVE AGREED TO A FEE OF: _____

I UNDERSTAND THAT I HAVE SOLE RESPONSIBILITY FOR ALL WITHHOLDING REQUIREMENTS AS MANDATED BY STATE AND FEDERAL LAWS, AS WELL AS PAYING ANY REQUIRED STATE AND FEDERAL TAXES.

AS I AM WORKING IN THIS HOUSEHOLD, I ACCEPT RESPONSIBILITY FOR MY PERSONAL SAFETY. I WILL NOT HOLD HOMEOWNER(S) FROM AND AGAINST ANY AND ALL CLAIMS, INCLUDING LOSSES, LIABILITIES, DAMAGES, COSTS AND EXPENSES INCURRED, REASONABLE ATTORNEY FEES AND COSTS ARISING FROM ANY INJURY OR ACCIDENT INCURRED WHILE PROVIDING SUCH SERVICES AS A CAREGIVER.

I HAVE BEEN INFORMED OF THE PATIENT'S CONDITION, DEMENTIA (POSSIBLY ALZHEIMER'S). MY DUTIES AND RESPONSIBILITIES INCLUDE, BUT ARE NOT LIMITED TO, PERSONAL CARE SUCH AS BATHING, EATING, DRESSING, TOILETING; EMOTIONAL CARE SUCH AS COMPANIONSHIP, STIMULATING ACTIVITIES, MEANINGFUL CONVERSATION; HOUSEHOLD CARE SUCH AS COOKING, CLEANING, LAUNDRY, SHOPPING; HEALTH CARE SUCH AS TAKING BLOOD PRESSURE, PULSE, AND TEMPERATURE AND REPLENISHING PRESCRIBED MEDICATIONS IN PILL BOX; AND REASONABLE ERRANDS. I AGREE TO A THREE-MONTH PROBATIONARY PERIOD.

THIS AGREEMENT CAN BE TERMINATED WITH A TWENTY-FOUR (24) HOUR VERBAL OR WRITTEN NOTIFICATION BY THE HOMEOWNER OR DESIGNATED REPRESENTATIVE(S) IF THERE IS EVIDENCE OF ABUSE OR REASONABLE RISK FOR ABUSE BY A CAREGIVER. OTHERWISE, A THIRTY-DAY NOTIFICATION FOR TERMINATION WILL BE GIVEN. THE CAREGIVER IS REQUIRED TO GIVE NOTIFICATION FOR TERMINATION OF CAREGIVER SERVICES PREFERABLY SIXTY (60) DAYS PRIOR TO THEIR NOTICE OF THE DISCONTINUANCE DATE, OR MINIMALLY, THIRTY (30) DAYS PRIOR TO THE DATE.

IN AGREEMENT:

Caregiver Signature

Date

Print Name of Caregiver

AD Representative or Primary Caregiver

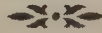
Date

(Note: Consult your attorney and accountant before using.)

APPENDIX: F

Date/Day of the Week:	Caregiver Name of Initials:
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DAILY REPORT LOG



NOTE: Include the appropriate activities in each area (i.e. meals, exercise routine, sleep patterns, outings, medication routine, bathroom and personal hygiene routine, behavior and mood changes, significant conversations, etc.)

MORNING (ENCOMPASSES BREAKFAST, AND FROM ABOUT 8 A.M-NOON)

Blood Pressure	Pulse	Temperature
----------------	-------	-------------

**AFTERNOON (ENCOMPASSES LUNCH, AND FROM
ABOUT NOON-6 P.M.)**

**EVENING (ENCOMPASSES DINNER, AND FROM ABOUT
6 P.M.-BEDTIME)**

SHIFT CHANGES: The house should be left the same way you found it – clean. Please check the following categories, indicating you have completed the appropriate chores:

1. Any incidents involving soiled clothes, sheets, etc. are cleaned and/or washed_____
2. All bathrooms are clean and smell fresh_____
3. All bedrooms are clean and smell fresh_____
4. Kitchen and den floors are swept and clean_____
5. On Sunday evenings, trash is put out on the curb_____

APPENDIX: G

OTHER DEMENTIAS



Frontal Temporal Lobe Dementia is characterized by a change in personality, poor impulse control, poor judgment, and often language impairment, *before* the onset of memory problems. Unlike AD, memory problems are symptoms that normally manifest *first*. Frontal temporal lobe dementia constitutes five percent of all dementias.

Multi-Infarct Dementia (MID), reportedly accounts for 10-20 percent of all dementias. It occurs when atherosclerotic cholesterol plaque in the arteries breaks off and blocks off small blood vessels in the brain, causing tissue death.

Parkinson's Disease is a neurological disease, and similar to AD, there is progressive damage of nerve cells, which is confined to the nerve cells in the area of the brain that controls movement. The initial symptoms are general shaking of the head and hands, loss of coordination, rigidity, and slow movement. As Parkinson's progresses, some patients show signs of dementia in the latter stages of the disease that appear similar to AD.

Pick's Disease is often referred to as a *prehensile dementia* because it occurs in younger adults. It is considered a rare disorder where brain atrophy occurs. On autopsy, abnormal substances called "Pick's bodies" are present in the nerve cells, usually in the frontal lobe and advances to the temporal lobes of the brain, at which point it can be

confused with AD. It differs from AD because there are no plaques or tangles on the brain, but patients have AD-like symptoms.

Huntington's Chorea causes degeneration of the nerve cells in the cerebrum. It is a hereditary condition caused by a gene mutation. It differs from AD because it is characterized by frequent abnormal facial and body movements, including quick jerking movements. It resembles AD in that personality changes, progressive loss of mental function, and loss of cognitive functions such as speech, calculative skills, and judgment occur.

Lewy Body Dementia is considered the second most common dementia diagnosis in most countries. It is widely accepted that this form of dementia starts in a different part of the brain than where AD begins. The criterion that distinguishes Lewy Body dementia from AD includes "fluctuations," from normal to almost delirious. The patient may be wildly confused, with a total resolution in hours.

Vascular Dementia can occur from a stroke that produces significant motor and cognitive impairment, or it can develop in a stepwise fashion as small strokes, often referred to as mini-strokes or Transient Ischemic Attacks (TIA's), occur.

APPENDIX: H

GLOSSARY OF TERMS



Alzheimer's Association – the only national voluntary nonprofit organization dedicated to conquering AD through research, providing assistance to individuals with disease, their families and caregivers through a vast nationwide network of chapters. Call (800) 272-3900 to locate the chapter nearest you.

Alzheimer's Disease – a disease of the brain that causes problems with memory, thinking and behavior. It is a type of dementia. It's not a part of normal aging.

Assisted Living Facilities (also referred to as a Residential Care Program) – provide a room, meals, supervision, social activities, and assistance with tasks such as dressing, eating, and bathing. They do not provide nursing or medical care. Residents usually must be able to walk and participate in their care.

Brain autopsy – removal of the brain at the time of death to examine the tissue for plaques and tangles only associated with Alzheimer's Disease. Currently a brain autopsy is the only way to prove or guarantee that the initial diagnosis of AD was accurate.

Clinical trials – a research study to find out whether new medicines or treatments are both safe and effective. Most often, clinical trials

take place at research centers and universities across the United States.

Cognitive skills – a patient’s ability to think, make and carry out reasonable plans, make judgments, have awareness and the ability to learn and retain new information.

Comfort care – keeping the patient pain free. It may include giving oxygen to help breathe better. It does not include giving drugs for an infection or fluids and food through a feeding tube.

Daily Living Activities (DLA) – the basic daily activities including bathing, dressing, eating, toileting, and sleeping that health professionals use to judge an AD person’s need for physical care.

Dehydration – a condition caused by lack of fluids in the body.

Dementia – a general term for the loss of memory and other intellectual abilities serious enough to interfere with daily life activities. AD is the most common form of dementia. Refer to Appendix 2 for a brief list of dementias that have some symptoms similar to AD.

Early Onset – refers to a type of AD that affects people who are under age 65. Many are in their 40’s and 50’s. This affects about ten percent of people with AD.

Fine motor skills – physical abilities requiring the use of small muscle groups in the hands, for example: buttoning shirts and tying shoe strings.

Functional skills – a patient’s ability to manage their own care and carry out their daily living activities such as personal hygiene, feeding, and grooming self.

Geriatrician – a physician who specializes in elder care.

Hallucinations – when a person sees, hears, smells, tastes, and/or feels something that isn't there. It can be a symptom of AD.

Home Health Care – a service that provides daily care and/or companionship in the home for the person with AD.

Hospice services – services that provide care for a person who is near the end of life and support for families during the time.

HMO – a health plan choice, short for **Health Maintenance Organization**.

Incontinence – generally refers to trouble controlling bladder and/or bowels. It is common for AD patients to begin to wet themselves or have bowel movements in their clothing. There are many causes of incontinence, so first you should consult a doctor.

Medicaid – combined federal and state government health care program for low-income people and families.

Medicare – a federal government health insurance program that pays some health care costs for people 65 and older.

Mild Cognitive Impairment (MCI) – characterized by memory impairment without impairment of other cognitive or functional abilities appropriate for normal age related memory. It could lead to AD.

Neuropsychological evaluation – a method of evaluating cognitive impairment as part of the diagnostic work up for AD. Normally it consists of a combination of questions, simple tasks, and observations of the patient.

Nursing home – a facility with trained staff to care for people who cannot care for themselves. They are inspected and regulated by the state government. In most cases, you have to pay for nursing home

care. Some nursing homes accept Medicaid as payment for care. Also, long-term care insurance may cover some nursing home costs.

Orientation – a patient’s recognition of time (i.e., day, year, time, holidays); and place (i.e.: country, state, town, facility, address, room).

Personal Alzheimer’s Disease Care Plan (PADCP) – a personal care plan developed by the author specifically for the patient in a home, preferably their home, which focuses on the patient’s strengths in performing their daily living activities and other activities special and unique to them.

Personal Care Home (PCH) – a patient’s home or a home where (s)he feels comfortable and has all the unique and special needs that are important to their well-being addressed.

Positron Emission Tomography (PET) – a scanning process that provides a picture of the brain at work. The image it produces shows which areas of the brain are working hardest during a particular kind of mentality activity.

Respite care – a form of temporary relief for the family caregiver. There is often financial assistance. Most often, it is a period of time off or away and is a way to reduce stress in the caregiver.

Tangles and plaques – while conducting an autopsy on a 51-year-old woman diagnosed with Early Onset Dementia, Alois Alzheimer discovered “neurofibrillary tangles.” He named the areas of marked deterioration “plaques.” Hence, AD was named after him.

Trigger – the reason for the way a person acts when they don’t like something or being somewhere, or what sets them off. It is often referred to as the alarms that go off in the brain prior to behavior challenges.

Safe Return Program – Alzheimer's Association provides an ID bracelet for AD patients who wander away from home or the caregiver.

Skilled Nursing Facility (SNF) – a skilled nursing homes that accept people who are medically ill and need total care. They also accept less disabled persons who may or may not be eligible for Medicare and/or Medicaid reimbursement. Medicare patients must have an acute condition for which they need skilled nursing for a short period of time.

Sundown syndrome – the occurrence of problematic behavior in the AD patient late in the afternoon or early evening.

Symptomatic drugs – they treat the symptom, not the root cause or etiology of a disease. They can't prevent or cure. For example, medications like Aricept and Exelon are symptomatic drugs, but can't slow down the progression of AD.

Strength-based concept – a way of thinking and a plan of care that focuses on identifying and incorporating the client's and/or family's strengths, rather than deficiencies in determining a viable treatment plan.

APPENDIX: I

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APPENDIX: J

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APPENDIX: K

MOVIES ABOUT DEMENTIA



‘Eight Informative and Entertaining Movies About Dementia You Should See’ is a list of films presented in the following order by Carrie Hill, PhD, About.com

About.com’s Health’s Disease and Condition content is reviewed by the Medical Review Board

These eight movies handle the difficult subject of Alzheimer’s Disease with grace, dignity, and realism. I hope that you find them useful and that they further support the points I drive home in *Stolen*.

1. Away From Her (2007)

In *Away From Her*, Julie Christie was Oscar-nominated for Best Actress for her portrayal of Fiona, a woman with Alzheimer’s who voluntarily enters a long-term care facility to avoid being a burden on Grant, her husband of 50 years. After a 30-day separation (recommended by the facility), Grant visits Fiona and finds that her memory of him has deteriorated and that she’s developed a close friendship with another man in the facility. Grant must draw upon the pure love and respect he has for Fiona to choose what will ensure his wife’s happiness in the face of the disease. Christie won a Golden

Globe Award for Best Actress in a Motion Picture (Drama) for her performance in this movie.

2. *The Savages* (2007)

Laura Linney and Philip Seymour Hoffman play siblings in this tragic comedy about adult children caring for a parent with dementia. Laura Linney was Oscar-nominated for Best Actress, and Tamara Jenkins was Oscar-nominated for best original screenplay. A rare combination of humility, dignity, and humor, Philip Seymour Hoffman was Golden Globe-nominated for Best Actor in a Motion Picture (Musical or Comedy) for his performance as the neurotic professor who begrudgingly unites with his sister for the sake of their father.

3. *Aurora Borealis* (2006)

Donald Sutherland and Louise Fletcher steal the show in this movie about relationships and difficult choices. Sutherland plays a grandfather with dementia who requires more care than his wife (Fletcher) can handle. They enlist the help of a home health aide (Juliette Lewis) and their grandson (Joshua Jackson), who forge a friendship as Sutherland's character – who insists he can see the Northern Lights from his window – becomes increasingly impaired. It was considered a well-crafted independent film that was released under the radar.

4. *The Notebook* (2004)-My favorite!

Based on Nicholas Sparks' best-selling novel of the same name, *The Notebook* features James Garner as Noah, the loving husband of Allie (Gena Rowlands), who is in a nursing home due to Alzheimer's. He attempts to rekindle her memories of their long history by reading to her from his notebook. Ryan Gosling and Rachel McAdams play the couple in their younger years. Described as a true romance, the movie was directed by Nick Cassavetes, son of Gena Rowlands.

5. *A Song For Martin* (2001)

Sven Wollter and Viveka Seldahl – married in real life – play married couple Martin and Barbara in this Swedish movie with English subtitles. Martin is a conductor and composer, Barbara, a violinist. They meet and marry in middle-age, but soon after, they find out that Martin has Alzheimer's Disease. This moving story is considered one of the most realistic depictions of caregiving on film.

6. *Iris: A Memoir of Iris Murdoch* (2001)

Based on the book *Elegy for Iris* by John Bayley, this movie tells the true story of English novelist Iris Murdoch's descent into Alzheimer's and the unconditional love of Bayley, her partner of 40 years. Jim Broadbent won an Academy Award and a Golden Globe for Best Supporting Actor for his portrayal of Bayley in his later years; Judi Dench and Kate Winslet received both Academy Award and Golden Globe nominations for Best Actress and Best Supporting Actress, respectively, for their portrayal of Murdoch in her older and younger years.

7. *Firefly Dreams* (2001)

This Japanese film with English subtitles won several international film festival awards. It tells the story of Naomi (Maho), a troubled teenager sent to the country for the summer to work for her aunt and uncle. She's asked to care for an aging neighbor with Alzheimer's; Naomi is initially unhappy about the arrangement, but soon connects with the woman in a transformative way.

8. *Age Old Friends* (1989)

Hume Cronyn achieves another great performance as John Cooper, who chose to live in a retirement home instead of live with his daughter (played by real-life daughter Tandy Cronyn) as a symbol of maintaining his independence. He befriends Michael (Vincent Gardenia), who starts showing signs of dementia. When

John's daughter extends her offer to live with her again, he must decide between leaving the rigid structure of the retirement home and staying to help his friend cope with his disease.

APPENDIX: L
PAGES FOR PERSONAL NOTES



CPSIA information can be obtained at www.ICGtesting.com
Printed in the USA
BVOW071344280413

319246BV00002B/4/P



Vascular dementia and AD are different
caregiver profile p 129

STOLEN

Alzheimer's Disease is no joke, to paraphrase Betty Davis who said, "Growing old is not for sissies." Lora King is triumphant in her magical mix of storytelling and educational information about AD. If you are a baby boomer, primary caregiver or in-home-caregiver, then you need to read this book and share it with every caregiver you know. I should know, I've been primary caregiver to my mother for years.

M.J. Duffy, author of
Lost Love, the Zankli Chronicles Book

Stolen is the honest story of a daughter's and son's efforts to be the primary caregiver for her aging father as he slips away into Alzheimer's Disease. It is inspiring and heart warming...a must read for any family caregiver.

Judy Wunsch, member of the Board of Directors of the Alzheimer's Association
California Southland Chapter.

While dealing with my dear father's illness...having conversations with Lora were like reading little excerpts out of her book, *Stolen*, that were helpful and insightful, and were gems that equipped me with stronger coping skills.

Karen Roache, of *Another Phase* by
Karen Roache, Jewelry Designer

Compelling indeed! And, yes, for those of us who have also struggled mute and naïvely with a loved one through this life annihilating disease – *Stolen* is long, long overdue! Having spent the better part of eight years as a full, hands-on witness and caregiver for my grandmother as she faded into the irreparable corners of her mind, it was good to be able to reflect on similar stories and events, with a bit of humor ... and a little healing. Would I have had this jewel of a book and the resources you have noted, life, however heartrending, would have been so much more an orderly journey rather than a series of urgent events. Thank you for the read, my dear friend. I have been bold enough to break this out into the open for more people to understand, take hold of the lessons and design their plans.

Ms. Donnel J. Loftin
Director/Coordinator – **ACTS:6 Ministries**

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